

***A QUALITATIVE STUDY OF THE EXPERIENCE OF
DELIRIUM IN OLDER PEOPLE AFTER HIP FRACTURE***

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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ABSTRACT

Delirium is a condition that is under-researched in comparison with equally common conditions (Adamis, Martin, Treloar & Macdonald, 2005). This is especially evident in the paucity of research into the lived experience of delirium. One group of patients who frequently become delirious is older people who have undergone surgery for a fractured hip.

This study examines the experiences of delirium in elderly hip fracture patients, to explore how people make sense of their experiences both while still in hospital and three-months later once they have been discharged. Nine older people who had experienced an episode of delirium following surgery for a fractured hip were interviewed in hospital. Four of these were interviewed three months later once they had returned home. Interpretative Phenomenological Analysis (Smith, 1995) was used to analyse the data collected from the semi-structured interviews.

Participants struggled to make sense of their experiences, and used defensive strategies to manage their anxieties. Participants appeared to have concerns about the implications of their experiences for their mental health, and the potential consequences for dependence on others. Some participants felt inadequately supported by nursing staff during their delirious experiences. At three-month follow-up participants still struggled to make sense of their experiences and the concerns they expressed did not appear to have substantially changed from the time they were in hospital.

Despite its small size, this study offers some important considerations for clinical practice. Possible avenues for future research are also discussed.

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Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
BDS	Blessed Dementia Scale
DRS	Delirium Rating Scale
GDS	Geriatric Depression Scale
ICU	Intensive Care Unit
IPA	Interpretative Phenomenological Analysis
LGI	Leeds General Infirmary
SMMSE	Standardised Mini Mental State Examination
NHS	National Health Service
UK	United Kingdom

Conventions

Direct quotes are presented in *italics*

Dialogue spoken by the researcher is indicated using the letter **R**

Where part of the text has been omitted, this is indicated by a series of 3 dots (...).

Straight brackets [] are used to present non-verbal information

INTRODUCTION

I first became interested in delirium while working as a nursing auxiliary on a surgical ward in a large NHS hospital in Birmingham shortly after completing my undergraduate degree in Psychology and Philosophy. Several of the patients had episodes of delirium during their stay in hospital, and would talk about bizarre topics, such as the installation of secret radios by the Japanese at one end of the ward. While travelling in India I became ill and during this time had several delirious experiences, for example hearing Cowboy and Indian films from the wall behind me (an outside wall). At the time I was uncertain of the accuracy of my experiences, but after the event had a better understanding of what was real and what cannot have been (although there are still some aspects that I am uncertain about). I became curious about how people made sense of these unusual experiences, and whether their understanding developed once the delirium had fully resolved. This became the basis for my thesis.

In this chapter I will discuss the clinical importance of researching delirium, and consider the small body of research into the lived experience of delirium. One group for whom delirium is particularly prevalent is older people who have undergone surgery for a fractured hip. The importance of exploring the experiences of this group will be considered, and the aims for the research stated.

Why Study Delirium?

Definition

Delirium (also known as *Acute Confusion*) is an acute condition defined as a disturbance of consciousness that is accompanied by a change in cognition that cannot be better accounted for by a pre-existing or evolving dementia. The disturbance develops over a short period of time, usually hours to days, and tends to fluctuate during the course of the day (American Psychiatric Association, 1994). *Disturbance of consciousness* refers to a reduced clarity of awareness of the environment and *change in cognition* refers to symptoms including memory deficit, disorientation, language disturbance or perceptual disturbance (e.g. misinterpretations, illusions or hallucinations). Delirium can be present in two contrasting clinical forms - *hyperactive*, where the patient presents in an active and agitated state - or *hypoactive*, where the patient appears withdrawn and in low mood. It is a fluctuating condition, and can change from one extreme to the other in the course of a single day (Lipowski, 1990). Delirium is

associated with the presence of a general medical condition, and as such has been referred to as a condition at the interface of psychiatry and medicine (Brown & Boyle, 2002).

Historical background

Delirium is one of the earliest mental disorders identified in medical history, with several references to the condition noted in the Hippocratic oath, making it around 2500 years old (Lipowski, 1990). Lipowski (1990) also notes that the that clinical descriptions of delirium have remained remarkably constant since the second century AD, although initially the two subtypes of delirium were described as separate conditions (*phrenitis* referring to the agitated presentation of hyperactive delirium and *lethargus* referring to the listless presentation of hypoactive delirium). While *phrenitis* and *lethargus* were described separately, it was recognised that one could change into the other, and that both accompanied fever. In the eighteenth century, the term *delirium* came to encompass both conditions (Lipowski, 1990).

The occurrence of delirium as a symptom of a somatic illness has been recognised from at least the second century AD, and recommendations for treatment dating back to the Ancient Greek and Roman writers included treating both the physiological and psychological needs of the patient. Lipowski (1990) notes that this dual approach can be seen as one of the most important contributions to medicine and psychiatry made by the ancient writers.

The importance of delirium in the understanding of mental illness has been emphasised by Berrios (1995). He argues that our understanding of delirium has formed the clinical model for the current ideas about psychosis. Lipowski (1990) in concluding his review of the history of delirium goes further, commenting that not only does the history of delirium represent an important chapter in the history of medicine and psychiatry but also *in the development of ideas about the nature of humanity, of mind, and of the mind-body relationship* (Lipowski, 1990, pg. 34).

Aetiology

There appears to be no one cause of delirium, rather it is associated with a wide range of physical conditions, including cancer, AIDS, post-operation and substance use or withdrawal. Several writers have observed that for most patients, multiple factors lead to the development of delirium (e.g. Brown & Boyle, 2002; Cole, 2004; Neelon, 1990). Prescribed drugs and acute infections may be the most common causes, especially in the elderly (Brown & Boyle, 2002).

Risk factors

The strongest risk factor for delirium is dementia, and a patient with dementia is five times more likely to develop delirium than a patient without dementia (Cole, 2004). Like delirium, dementia is characterised by multiple cognitive deficits (American Psychiatric Association, 1994). The phenomenological aspects of both are very similar (Cole, McCusker, Dendukuri & Han, 2002; Trzepacz, Mulsant, Dew, Pasternak, Sweet & Zubenko, 1998) and nurses frequently have difficulty in distinguishing the two conditions (Fick, Agnostini & Inouye, 2002; McCarthy, 2003). The clinical course can help distinguish delirium from dementia. While in delirium symptoms typically fluctuate, symptoms in dementia are relatively stable (American Psychiatric Association, 1994).

Delirium may worsen the prognosis of pre-existing dementia and has also been associated with the subsequent development of dementia (Fick *et al.*, 2002). The co-morbidity of delirium and dementia has been associated with an array of negative outcomes, including longer hospital stays, increased likelihood of readmission to hospital, decline in physical and cognitive functioning and death (c.f. Fick *et al.*, 2002). Difficulties in detecting delirium superimposed on dementia and the associated delay in identifying the underlying cause of delirium may contribute to the poor outcomes (Fick *et al.*, 2002).

Age is a risk factor for delirium, with the young and old being particularly susceptible (Brown & Boyle, 2002). Risk of delirium is also higher in severely ill patients (Cole, 2004). In addition, environmental issues such as sensory impairment (sight or hearing), sensory deprivation and moving to a new environment have been reported to increase the risk of delirium (Brown & Boyle, 2002).

Prevalence of delirium

Delirium is one of most common psychiatric complications in general hospitals (Lipowski, 1990). Hospital prevalence rates for delirium have been reported to range from 10% – 66% depending on the reason for hospitalisation (c.f. Brown & Boyle, 2002; Cole, 2004).

In the community, prevalence rates have been reported at 1-2% (Folstein, Bassett & Romanoski, 1991, cited in Cole 2004). However, Brown & Boyle (2002) note that changes in health care practice such as shorter hospital stays and an increase in day surgery is likely to make delirium an increasingly common problem in the community and residential care homes. In line with this, they report that it has been estimated that less than half of patients with delirium are fully recovered by the time they are discharged from hospital.

Detection of delirium

Despite its prevalence, detection of delirium is poor. Brown & Boyle (2002) note non-detection rates of up to 66% have been reported. One reason for this is that healthcare professionals may expect patients to present with hallucinations and agitation, (the *hyperactive* form) whereas many present with *hypoactive* symptoms which are missed (Cole, 2004). The fluctuation of symptoms in delirium also makes it difficult to assess, especially for doctors who only spend a short amount of time with the patient. It is therefore nursing staff who record most observations of acute confusion (Cole, 2004). However, nurses' ability to detect delirium has been reported to vary widely, and is often compounded by the lack of skill in assessing mental status and differentiating delirium from other conditions, especially dementia (Fick, *et al.*, 2002; McCarthy, 2003).

Delirium and outcome

Even after controlling for other variables such as severity of illness, the presence of delirium predicts longer hospitalisation and poorer outcome for patients. Complications can include fractures from falls caused by wandering, pneumonia caused by inactivity or even death due to the failure to treat the associated medical condition (Brown & Boyle, 2002). In addition, delirium can impact on the assessment of other symptoms in ill patients, such as the ability to perceive and report pain (Hallström, Elander & Rooke, 2000).

Management of delirium

Treatment of delirium is centred on the management and treatment of the conditions which precipitate the delirium (Cole, 2004). Environmental interventions are also recommended, to minimise the demands made on the patient with impaired cognitive functioning, for example by providing orienting stimuli (such as clocks and calendars) and ensuring appropriate sensory aids are present (such as glasses or hearing aids) to help the patient accurately interpret the environment (Foreman, Mion, Tryostad & Fletcher, 1999).

In addition, some authors have recommended psychological support, such as the opportunity to discuss their experiences once the confusion has resolved (Mackenzie & Popkin, 1980; McCurren & Cronin, 2003; Schofield, 1997).

Recall of the delirious experience

While there has been some suggestion that the occurrence of delirium may negatively effect memory (e.g. Schacter, 1996, cited in Jones, Griffiths & Humphries, 2000), much research indicates that for many people at least partial memory of the delirious experience is preserved. For example, a quantitative study of cancer patients by Breitbart, Gibson & Tremblay (2002)

found that 53.5% recalled their delirious experiences. They reported that patients were more likely to recall their experiences of confusion if the delirium had been mild (100% recall for mild delirium, 55% for moderate delirium and 16% for severe delirium).

Reflections on the literature

Delirium appears to be an interesting and important area of research, with much evidence of high prevalence rates and association with negative outcomes in hospitalised patients.

However, as Lipowski (1990) comments *Despite its long history, delirium remains a poorly understood mental disorder, yet one that raises fundamental questions about the nature of the brain – behaviour relationship and its disturbances* (pg. 4). One aspect of delirium that has been little researched is the lived experience of delirium, and how patients make sense of their experiences of delirium. Increased understanding of the lived experience of delirium may help inform healthcare professionals how to better support the psychological needs of delirious patients. In the next section I will review the existing literature on the experience of delirium.

The Experience of Delirium

A handful of studies have focused on the experiential aspects of delirium. I will discuss their findings in this section. Strategies used for literature searches can be found in Appendix A.

The experience of delirium

Studies exploring the phenomenological aspects of delirium have reported a range of experiences during the confusion.

Confusion of time and place

Confusion about time and place is a key theme in several qualitative studies of delirium. In a case study of an elderly woman who became delirious following surgery for a fractured hip, Andersson, Knutsson, Hallberg & Norberg (1993) note that her experience involved the merging of past and present. Later studies by Andersson and colleagues have indicated similar findings. Andersson, Norberg & Hallberg, (2002a) recruited fifty-one older people who developed delirium while in hospital for orthopaedic surgery in Sweden and used non-participant direct observations to investigate the experience of delirium while the patients were actively delirious. They noted that participants appeared to bring people, places or events from their past into the present, and use experiences from their past to explain and act on in the present (for example talking about visiting a restaurant while still in hospital).

Once their delirium had resolved, Andersson and colleagues interviewed fifty of the orthopaedic patients whom they had observed (Andersson, Hallberg, Norberg & Edberg, 2002b). A phenomenological hermeneutic analysis was employed to uncover the meaning of their delirious experiences for the participants. A key theme for participants was that while delirious they appeared to be encountering past, present and imagination as reality, which the authors described as *being in a borderland* (pg.657).

Similarly, using a phenomenological hermeneutic approach to analyse the interview of ten patients who had been confused while in a Finnish Intensive Care Unit following cardiac surgery, Laitinen (1996) noted that participants appeared to be *on the border of awareness of space and time* (pg.80).

Detachment from reality

As well as being confused about past and present, some authors have noted that feelings of detachment from reality were described by participants in their studies. Schofield (1997) used grounded theory methodology to explore the reactions of nineteen older people to an episode of delirium in a NHS hospital. She noted that some participants talked about feeling separated from the events going on around them. McCurren & Cronin (2003) reported similar findings. They interviewed fourteen older people in America about their experiences of delirium and commented that participants reported a general sense of *fuzziness* and detachment from reality.

Difficulties concentrating

In their observations of elderly orthopaedic patients with delirium, Andersson *et al* (2002a) noted that participants were incoherent in their speech, and frequently switched between topics. Similar findings have been noted by Fagerberg & Jönhagen (2002). They interviewed five older people from a Swedish outpatient clinic who had experienced an episode of confusion within the last year, and used a phenomenological method to analyse their data. They reported that participants described feeling as if their senses were *wide open* (pg. 342), able to perceive everything that went on around them, but not able to concentrate on one specific thing.

Hallucinations and Delusions

Schofield (1997) noted that just over half of the patients in her study reported perceptual disturbances, which included illusions, hallucinations and delusions. Other studies of the experience of delirium have reported participants described similar experiences (e.g. Andersson *et al* 2002a; Fagerberg & Jönhagen, 2002; McCurren & Cronin, 2003).

How do people make sense of an episode of delirium?

Several qualitative studies investigating the lived experience of delirium have explored the way participants have made sense of their experiences of delirium. Andersson *et al* (2002a) observed that while delirious, patients appeared to struggle to understand and gain control of their experiences. In the authors' interviews with participants once the delirium had resolved (Andersson *et al.*, 2002b), they reported that this struggle to make sense of their experiences was still evident. Participants appeared to be trying to get a grip on the experience of confusion and to confront the idea of having been confused. These patients appeared to have a strong desire to make sense of their confusion and to gain control over their situation. They explained their confusion in terms of factors outside of their control, such as strong medication, the trauma, the surgery, pain and fatigue. However, it is important to note that participants in these studies were given information about the study and informed of the possibility that they may develop delirium on arrival to hospital. This information is likely to have influenced their causal attributions.

Several authors have reported that patients with delirium use life stories and past experiences to try to make sense of their experiences while delirious (e.g. Andersson *et al.*, 1993; Andersson *et al.*, 2002b). However, this cannot always be successfully done. Fagerberg & Jönhagen (2002) reported that despite searching for connections between their experiences and their private lives, participants were unable to find any connections to help them make sense of their experiences.

Crammer (2002) reported on his own experience of delirium following acute renal failure. In trying to make sense of his confusion, the author described looking for events in reality which may have influenced his delusional beliefs (e.g. thinking he was being transferred to Australia may have been due to the presence of Australian nurses).

Not all patients try to understand their experiences, however. Schofield (1997) reported surprisingly little curiosity from patients in her study about what caused their delirium. Similarly, McCurren & Cronin (2003) reported that while some participants strove to make sense of what had happened, others seemed to be trying to forget the whole experience.

Reactions to the delirious experience

Studies investigating the lived experience of delirium have reported a variety of emotional responses to the experience of delirium.

Breitbart *et al.*, (2002) developed a quantitative measure to look at the phenomenological aspects of delirium in patients with cancer. They reported that 80% of patients who could recall their delirium reported severe distress at their experiences. Patients with *hypoactive* delirium reported as much distress as patients with *hyperactive* delirium.

In qualitative studies of delirium, participants have reported feeling threatened, frightened or anxious while delirious (e.g. McCurren & Cronin, 2003; Fagerberg & Jönhagen, 2002), and remembered their illusions and hallucinations as unpleasant or sinister (Schofield, 1997). Paranoia and suspicion about medical staff have also been reported (Andersson *et al.*, 2002b; Fagerberg & Jönhagen, 2002).

The feeling of loss of control is a theme raised by participants in several studies of delirium, which aroused feelings of frustration and helplessness (e.g. Andersson *et al.*, 2002b; McCurren & Cronin (2003). In addition, feelings of shame, guilt and humiliation are common reactions described by patients who have experienced an episode of delirium, both while delirious (Andersson *et al.*, 2002a) and after the delirium has resolved (Andersson *et al.*, 1993; Andersson *et al.*, 2002b; Fagerberg & Jönhagen, 2002; Laitinen, 1994; McCurren & Cronin, 2003). Participants in Fagerberg & Jönhagen's (2002) study reported fear of recurrence.

While the majority of reactions to an episode of delirium reported in the literature are very negative, Andersson *et al.* (2002a) noted that some patients had more positive responses to their experiences. For example, one participant in their study commented *I want to keep that dream about the washerwoman, because it was so nice* (pg.309).

Longer-term consequences of delirium

While many of the studies have investigated the experience of delirium retrospectively, most have interviewed participants immediately after the delirium has resolved, while they are still in hospital. Very little research has been conducted to explore the longer-term impact of delirium.

Fagerberg & Jönhagen, (2002), studied patients who had been delirious within the last twelve months. The authors reported strong feelings by the participants, including fear of recurrence while at home. However, the focus of this study was to explore what participants experienced while delirious and how they made sense of these experiences to enhance nursing care of actively delirious patients. Longer-term consequences were not explicitly reported. It may be that further exploration of the current impact of delirium on these patients would have revealed more themes, such as concerns about future hospital experiences.

Mackenzie & Popkin (1980) discussed the stressful impact of an episode of delirium on a 50-year-old woman with heart disease. Discussions with the woman ten months after discharge indicated that she was experiencing symptoms of post-traumatic stress, including recurrent nightmares about her delirious experiences.

Longer-term consequences have been observed for patients who have experienced an episode of confusion while in the Intensive Care Unit (ICU). Granberg, Engberg & Lundberg, (1999) commented that in their study of the experiences of patients who had been ventilated in a Swedish ICU, one man reported that his *stupid fantasies* continued after leaving the hospital. Fleminger (2002) discussed the experience of one patient who had been in an ICU and who remained distressed for months because he believed his delusions about nursing staff stealing equipment. Similarly, Russell (1999) reported that six months after discharge from ICU some patients continued to be ashamed or terrified by their experiences which sometimes prevented a full psychological recovery. This is in line with comments by Jones *et al.*, (2000), who reflected that memories of frightening hallucinations, delusions or panic while in the ICU may hinder a patient's psychological recovery.

Reflections on the literature

The small body of research investigating the lived experience of delirium indicates that many patients find themselves struggling to make sense of the confusion they have experienced, and that these experiences are frequently associated with distressing emotions such as fear, shame and guilt. Very little research has examined the longer-term consequences of delirium.

It is important to note that the majority of studies of patients' experiences of delirium on general wards have recruited participants on the basis of observations of delirious symptoms by nursing or medical staff (Andersson *et al*, 2002a; 2002b; Fagerberg & Jönhagen, 2002; McCurren & Cronin, 2003; Schofield, 1997). However, healthcare professionals frequently under-diagnose delirium, especially those who do not present with *hyperactive* symptoms (Fick, *et al*, 2002), so it seems likely that these studies suffer from a selection bias. Only the single case studies and studies of delirium in the ICU have not relied on healthcare staff to diagnose delirium.

In addition, the literature on the lived experience of delirium is drawn from diverse populations. Some studies recruited participants hospitalised for a variety of medical reasons

or failed to specify reasons for hospitalisation (McCurren & Cronnin, 2003, Fagerberg & Jönhagen 2002; Schofield, 1997). Those studies which did give clear indication of the population that they were studying involved patients from very different groups, including patients with cancer (Breitbart *et al.*, 2002) elderly orthopaedic patients (Andersson *et al.*, 1993; 2002a; 2002b), cardiac patients (Laitinen, 1996; Mackenzie & Popkin, 1980), a renal patient (Crammer, 2002) and patients who had been in the Intensive Care Unit (Fleminger, 2002; Granberg *et al.*, 1999; Laitinen, 1996; Russell, 1999). In addition, while age range is specified in several studies (Andersson *et al.*, 1993; 2002a; 2002b; Crammer, 2002; McCurren & Cronnin, 2003, Fagerberg & Jönhagen 2002; Schofield, 1997), in others this is not mentioned (Fleminger, 2002; Granberg *et al.*, 1999; Laitinen, 1996; Russell, 1999). It seems likely that the context of a delirious episode may influence the way in which an individual makes sense of their experiences. For example, in the ICU a range of factors may apply, including sleep deprivation and anxiety due to the immediate danger of death. The experiences of these patients may be very different from patients who experience delirium on a general medical or surgical ward. Similarly, a patient with end-stage cancer approaching death may view an episode of delirium differently than a patient who is in hospital following a hip fracture, who may reflect on the experience both during hospitalisation and on recovery. In addition, the age of a patient may affect the impact of an episode of delirium. For example, an episode of delirium may be more likely to cause concern about permanent changes in cognitive functioning in older patients than in younger people. Research on the experience of delirium in a homogenous group of patients could provide valuable insights into the best way to care and support patients. One group of patients where delirium is particularly prevalent is older people following surgery for a hip fracture. I will discuss this in the next section.

Delirium in Older People Following Hip Fracture

Prevalence and outcome

Around 50,000 hip-fractures occur each year in the UK (Archibald, 2003) and it is estimated that this number will at least double by 2050 (The British Orthopaedic Association, 2003). High rates of delirium have been reported among this group. Holmes & House (2000a) conducted a systematic review and reported rates of 43-61% for delirium and 31-88% for unspecified confusional state (dementia & delirium).

A variety of negative outcomes have been found to be associated with the experience of delirium during hospitalisation in hip fracture patients, including increased length of hospital

stay, increased physical dependence, decreased likelihood of independent living on discharge from hospital and decreased survival rates at 6 months post discharge (Holmes & House, 2000b).

In order to better understand the impact of hospitalisation, it is important to consider the lived experience of these individuals. Before considering the experience of delirium, I will discuss the context of the experiences of older people in hospital with a fractured hip. Very few studies have been conducted specifically exploring the experiences of elderly fracture patients, so I will initially look at themes from the wider literature of older people's experiences of hospitalisation, before focusing on issues arising from studies of elderly hip fracture patients. Details of the strategies used for searching the literature can be found in Appendix A.

Older people's experience of hospitalisation

Research exploring the experiences of older people in hospital and the impact of their experiences after discharge has revealed some interesting themes.

Huckstadt (2002) looked at the experience of eight hospitalised older people in America, and commented that while illness and hospitalisation can be a stressful situation for anyone, regardless of age, this is more likely to be true for older people, who may be less likely to adapt to hospitalisation. She reported that participants in her study perceived hospitalisation as a stressful event with many threatening factors.

Krevers, Närvänen & Öberg (2002) looked at the needs and concerns of elderly patients in Sweden throughout the care process. They reported that patients described different needs during different phases of hospitalisation.

Concerns during hospitalisation

Participants in Krevers *et al.*'s (2002) study identified a range of needs including physical, psychological and social needs.

A key theme identified by several researchers, as well as by observations of clinicians working in a geriatric setting, is that of boredom and lack of attention given to patients. For example, Koch, Webb & Williams (1995) reported that participants in their study of older patients within the NHS commented on the lack of nursing attention, and described periods of time waiting for nurses to address their needs. Participants reported that there was a lack of attention in many areas of care, including food, safety, comfort and hygiene. Participants in this study felt unable to complain to staff.

Another important issue for many hospitalised older people is the experience of being treated as less than a responsible adult, with staff perceiving older patients as having declining cognitive abilities. (Koch, *et al.*, 1995). In addition, older patients have described a struggle between dependence and independence – having to ask for assistance in some activities of daily living, but wishing to maintain a sense of autonomy (Huckstadt, 2002). Krevers, *et al.*, (2002) observed that participants in their study felt that dependency had led to an infringement of their integrity. Similarly, Jacelon (2003) noted that the five elderly patients she interviewed about their experiences of hospitalisation in America reported that they felt their dignity was affected by medical procedures and interactions with staff throughout the care process.

Concerns after hospitalisation

Some studies have looked at the concerns expressed by older people after discharge from hospital. These indicate that patients worry not only about their own health and how they will manage their daily lives, but also the impact of their illness on their care-givers (Huckstadt, 2002; Krevers, *et al.*, 2002). Krevers and her colleagues also commented that older people's psychological well-being could be affected by expectations about the future, creating worry and anxiety about their current state of health.

Making sense of the experience of hospitalisation

Researchers have also looked at factors which influence older people's interpretation of their experiences in hospital. Several authors have reported that past experiences of hospitalisation, both their own and the experiences of people close to them, influence the way older people make sense of their current hospital experience (Huckstadt, 2002; Krevers *et al.*, 2002). Ryan and Robinson-Smith (1990) suggest that the meaning individuals ascribe to their experiences of hospitalisation may contribute to their concept of self and the authors suggest that helping patients find meaning may ameliorate psychological problems.

Older people's experiences of hospitalisation following hip fracture

A handful of studies have explored the experience of hospitalisation in older people with a hip fracture. In addition to the themes reported in the above studies, certain issues particular to hip fracture have been identified.

Through interviews with older people in America living in the community who had not experienced a hip fracture, Furstenberg (1986) observed that older people are apprehensive about the prospect of fracturing a hip, and foresaw a difficult recovery and problems regaining their previous lifestyle. The participants she interviewed who were in hospital following a hip fracture moderated their expectations on the basis of their perceived progress and information

from health professionals, although concerns about the implications of their limited functioning were still prominent. This is also in line with comments made by the participants of Robinson's (1999) study looking at the transitions in the lives of older women in America who have experienced hip fracture. Similar concerns have been noted by Archibald (2003), who used a phenomenological methodology to analyse interviews of five older people in the UK about their experiences of hip fracture. He noted that a key factor for many older people who experience a hip fracture is the limitation in mobility and uncertainty about if and when they would return to previous level of functioning.

Dependency on others due to physical disability following a hip fracture was identified as a concern for participants in these studies (Archibald, 2003; Furstenberg, 1986; Robinson, 1999). Robinson (1999) observed that while feelings of dependency and lack of control may have a negative impact on recovery after a hip fracture, accepting help and being able to make adaptations to tasks of daily living were important function-promoting factors.

None of the above studies have discussed the issue of delirium on hip fracture patients. However, some researchers have considered the presence of delirium in hip fracture patients.

The impact of delirium on hip fracture patients

Brännström, Gustafson, Norberg & Winblad (1989) explored the impact of delirium in elderly hip fracture patients on areas of basic nursing care. They identified two main areas of problems in the patient group studied; the predictable physical consequences of fracture, surgery and hospitalisation, and problems specifically related to acute confusion (namely disorientation, distractibility and disturbances in perception and interpretation of stimuli). They reported that significantly more delirious patients had problems in nine of the fourteen aspects of nursing care looked at, with qualitative differences in all areas except breathing and circulation. Delirious patients were more likely to put themselves in risky situations and had more difficulty in remembering instructions and communicating with staff. In addition, delirious patients were more dependent in activities of daily living than non-confused patients.

Bowman (1997) used structured interviews to look at sleep satisfaction and pain in elderly orthopaedic patients and reported that both were worse in patients who had experienced an episode of delirium. Similarly, Hallström, *et al.*, (2000) investigated pain and nutrition in hip fracture patients. They reported that delirious patients had more problems in communicating pain, suggesting that they may not have adequate pain management.

Andersson and colleagues explored the lived experience of delirium in elderly orthopaedic patients in Sweden, most of whom were hospitalised following a hip fracture (Andersson *et al.*, 1993; 2002a; 2002b). However, these studies concentrated on the experience of delirium and little in their discussion linked the delirious experiences to the experience of being in hospital following orthopaedic surgery in particular.

Reflections on the literature

Delirium is a prevalent and problematic issue for older people hospitalised following a hip fracture, and is associated with a range of negative consequences including increased length of hospital stay, increased physical dependence, and potentially poor pain management (Hallström *et al.*, 2000; Holmes & House, 2000a).

Literature on the experiences of older people in hospital suggest that even without delirium they feel undignified and treated as having declining cognitive skills (Koch *et al.*, 1995). It seems important to consider how an episode of delirium may add to this experience.

In addition, older people use past experiences of being in hospital to make sense of the experience of current hospitalisation (Huckstadt, 2002; Krevers *et al.*, 2002). If past experience of being in hospital involves an episode of delirium, it seems crucial to explore the impact this may have on attitudes to future hospitalisations.

Older people recovering from a hip fracture have much to contend with as they acknowledge their physical frailty and work to regain their previous functioning. Brown & Boyle's (2002) observation that delirium is not resolved at discharge for over half of patients, suggests that some of these individuals may have to contend with some level of cognitive impairment, as well as their physical impairment, at discharge from hospital. In addition, the longer-term impact of delirium has not been discussed in the literature. It may be that reflections on the delirious experience are influenced by concerns about the continuing physical frailty experienced by those recovering from a hip fracture, particularly if the delirium is not fully resolved at the time of discharge from hospital.

While Andersson and colleagues have qualitatively explored the experience of delirium in elderly orthopaedic patients in Sweden (Andersson *et al.*, 1993; 2002a; 2002b) they did not specifically explore the relationship between the experience of delirium and the experience of hospitalisation following hip fracture. In addition, as different countries utilise different

models of health care, it seems important to explore the experience of patients within a UK setting to best inform NHS provision for these patients.

The Current Research

The aim of the current research is to qualitatively explore the ways in which older people make sense of an episode of delirium after they have undergone surgery for a fractured hip, both while still in hospital and three months later.

Clinical relevance

The National Service Framework for Older People has called for staff skills to be better matched to the needs of patients in general hospitals, and for improvements in the prevention, care and treatment of mental health problems (Department of Health, 2001). One way to help meet these aims is by enhancing understanding of the patient's experience of hospitalisation. A qualitative study of the experiences of delirium in older people hospitalised following surgery for hip fractures could inform professionals' understanding and choice of intervention with this patient group, and allow skills to be developed that better match the needs of these individuals. Follow-up interviews will help determine if these individuals have ongoing and unmet needs concerning their experiences of delirium, and reflect on how best to provide support for these individuals.

Context of departmental research

The Academic Unit of Psychiatry and Behavioural Sciences and the Faculty of Health at the University of Leeds has an established research and clinical interest in delirium, and is developing a multidisciplinary research programme in this area. Projects previously undertaken by the department include research into the prevalence and prognosis of delirium in general hospital populations. Current research within the department includes a systematic review of prevalence, prognosis and interventions for delirium; an epidemiological study of delirium in vascular surgery; an evaluation of liaison mental health services; an examination of the training needs of general nurses working with patients with delirium and the development of a complex intervention to improve the management of delirium. In the future, it is planned to validate a delirium rating scale and to evaluate a complex intervention for delirium. The current study exploring the lived experience of delirium and its longer-term effects on psychological functioning will therefore provide an important component of the wider research programme to increase understanding of the nature and impact of delirium.

Questions to be explored

- ❑ How do older people who become delirious after reparative hip fracture surgery make sense of their experiences in the context of their lives while they are still in hospital?
- ❑ What sense do they make of their experiences after three-months?
- ❑ Are there implications for their thoughts about future hospitalisations?

METHODOLOGY

The Methodology chapter is presented in three sections. Initially, I will consider theoretical aspects of the methodology and justify the approach taken. I will then consider the ethical issues involved in the research. In the final section I will describe the methods used in the research.

Theoretical Methodology

Qualitative approaches in psychology

Qualitative approaches are becoming increasingly popular in psychological research, in particular when applied to clinical psychology and health research (Turpin, Barley, Beail, Scaife, Slade, Smith & Walsh, 1997). Unlike quantitative research, qualitative studies offer participants the opportunity to describe the rich complexities of their experiences as they live through situations, and the researcher attempts to understand as much as possible from the perspective of the participants (Elliott, Fischer & Rennie, 1999). As Stiles (1993) comments, *People react and change qualitatively* (pg. 596).

The aim of my research is to explore the lived experience of delirium and the ways in which participants make sense of these experiences both while in hospital and at three-month follow-up. This fits clearly with a qualitative approach.

Epistemology

Within qualitative research there are a number of different epistemological and methodological positions. When undertaking a research project, it is important to be clear about the epistemological stance of the researcher, and to ensure that the methodology chosen fits with this theory of knowledge (Fossey, Harvey, McDermott and Davidson, 2002). I will briefly discuss three major epistemological frameworks and state which stance I have taken for this research project. I will then consider possible methodologies consistent with my chosen position, and explain my decision for opting for the methodology used.

Realist / positivist position

The realist or positivist position is usually associated with quantitative studies and fits with empirico-analytic methods of research (Fossey *et al*, 2002). It holds that there is an objective reality, which can be discovered through processes which are taken to be objective and value-

free, such as observation and deductive logic (Fossey *et al*, 2002). While some qualitative methodologies have adopted this stance, such as content analysis (Fossey *et al*, 2002) and some proponents of Grounded Theory (c.f. Charmaz, 1995), Fossey *et al*. (2002) note that it is not well equipped for understanding subjective experiences, the meanings given to experiences, or intersubjective interactions.

Contextual Constructionist framework

The contextual constructionist paradigm contests the idea that there is one objective reality, instead viewing all knowledge as local, provisional and context dependent and emphasising the subjectivity of the way we perceive the world (Madill, Jordan & Shirley, 2000). Interpretative methods of research are used in line with this position, being interested in the way individuals experience the world, and in developing understandings of the meanings of experiences and actions (Fossey *et al*, 2002).

Radical Constructionist position

The radical constructionist position takes a step closer to contesting the idea that there can be absolute foundations for knowledge (Madill *et al*, 2000). It is associated with post structuralism (which rejects the idea that there is one 'self' - people are seen to hold multiple identities which are socially and culturally produced and maintained) and questions the idea that language can represent reality, as knowledge is considered to be a discursive construction (Madill *et al*, 2000). Critical research methodologies are used in line with this position, and examine the ways thinking and discourses are culturally and historically constructed, and how this confines our actions (Fossey *et al*, 2002).

The Epistemological stance taken.

The three positions outlined offer very different ways of viewing the world and ideas about how knowledge can be obtained. The positivist position takes little account of the subjectivity of experience, and so does not appear consistent with research which focuses on the lived experience of delirium. At the other extreme, the radical constructionist position contests the idea that there can be any absolute basis for knowledge, and examines the way discourses shape notions of self and experience. This emphasis on cultural discourses does not fit with the research aims. The contextual constructionist position sits somewhere in the middle. This seems to be the most in line with the aims of the research, focusing on the subjective view of participants' experiences of delirium and is the position adopted for this research.

Methodologies

There are several methodological approaches which fit with a contextual constructionist approach. In this section I will consider three of the most prominent, and consider which is best suited to the current research.

Discourse Analysis

Discourse Analysis refers to a group of methodologies whose focus is the role of language in the construction of the social world.¹ The focus of Discourse Analysis is on what is said, and it does not attempt to look for underlying mental states, but rather examines the way in which language is used to construct the world and manage social interactions (Willig, 2001).

Grounded Theory

Grounded Theory was designed by sociologists (Glaser & Strauss) to identify and help explain social processes (Willig, 2001). As its name suggests, the development of theory is a key component of Grounded Theory. It takes a “bottom up” approach, allowing theories to emerge from the data through a process of induction. However, Willig (2001) comments that the emphasis on uncovering social processes limits the applicability of Grounded Theory to more phenomenological research questions.

Interpretative phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) offers a method for exploring the *lived experience* of participants, and how they make sense and meaning from these experiences (Smith, 2004). Unlike Discourse Analysis, IPA is interested in trying to understand the thoughts and beliefs of an individual and assumes a connection between what people say and their thinking and emotional state (Smith & Osborn, 2003).

IPA has its philosophical roots in the traditions of *Phenomenological Psychology* and *Symbolic Interactionism*. Phenomenological Psychology, is based on the Husserlian idea that we cannot separate objects or events from our experience of them, and that our experiences will necessarily be dependent on their context, including the mental context of beliefs, desires, judgements, emotions etc. (Willig, 2001). Phenomenological Psychology is interested in an individual’s personal perception of an object or event, rather than in trying to make a general

¹ While some Discourse Analysts follow a critical realist paradigm, looking at the political and ideological functions of macro level societal discourses (e.g. Parker, 1992), other forms of Discourse Analysis fit within a contextual constructionist epistemology (e.g. Potter & Wetherall, 1995)

statement about the object or event itself (Smith, 1996). Symbolic Interactionism emphasises the *meaning* that an individual ascribes to an event, and argues that social interaction provides the context and the process in which meanings occur, and are made sense of. Symbolic Interactionism stresses that the meanings of an event to an individual are only obtained through interpretation (Smith, 1996). IPA is phenomenological in that it is interested in an individual's perception of an object or event, rather than in the object or event itself, and interpretative in using researcher's own conceptions to make sense of participant's personal world through a process of interpretative activity (Smith, Jarman & Osborn, 1999).

IPA attempts to get as close as possible to an 'insider perspective' in exploring the participant's view of the world while acknowledging that it is not possible to access a participant's personal world directly or completely. Any understanding of the person's world is necessarily dependent on, and complicated by, the conceptions of the researcher (Smith, 1996). IPA also encourages critical engagement with the material and allows the reader to ask questions and suggest interpretations which the participants may be unlikely or unwilling to see themselves (Smith, 2004).

Methodological approach taken

The concern of the current study is to look at the lived experiences of delirium, and the meanings and interpretations given to these experiences by the individual. Research into the lived experience of delirium requires analysis that goes beyond an examination of linguistic devices. Therefore, Discourse Analysis does not appear to be an appropriate methodology. Willig (2001) has noted that the emphasis of Grounded Theory on uncovering social processes may restrict its applicability to the phenomenological questions of the current research. In addition, the emphasis on generating theory does not explicitly fit with the aims of this research project. IPA offers a method for exploring an individual's perception of an event and seems a well-suited methodology for this study. In addition, the use of IPA in health research has been advocated by Smith and his colleagues (Smith, 1996; Smith *et al.*, 1999). They suggest that an exploration of the way in which different individuals talk about what is medically categorised as an equivalent condition *may help to illuminate the subjective perceptual processes involved when an individual tries to make sense of his or her health condition* (Smith *et al.*, 1999, pg. 219).

Producing data

Qualitative researchers can employ a variety of tools to produce data about the area being studied. Three of the main techniques are focus groups, structured interviews and semi-structured interviews. These will be discussed below.

Focus Groups

A focus group is a discussion-based interview involving the use of multiple respondents, which allows the researcher to gain insight into the perspectives of participants on the issues being discussed (Millward, 1995). Data generated from discussion groups is influenced by the dynamics of the group, and interpretation of the results must be understood in the context of the group interaction (Millward, 1995).

Structured Interviews

In structured interviews, the researcher typically decides in advance what data is required and questions are formulated in a way that elicits data corresponding to pre-determined categories (Smith, 1995). The respondent may be asked to choose from a set of possible answers, or may be allowed to give free answers which are then categorised (Smith, 1995). Structured interviews can be useful if the researcher is already aware of the themes to be looked for. However, structured interviews have been criticised as too constrained, limiting what the respondent talks about to areas pre-decided by the researcher and often preventing exploration of complexity or ambiguity (Smith, 1995).

Semi – structured interviews

In semi-structured interviews although the interviewer develops questions on an interview schedule, these are designed to guide the interview rather than dictate it (Smith *et. al.*, 1995). While the interviewer has some ideas about the areas of interest, the respondent is more involved in the direction the interview takes and can introduce an issue that the investigator may not have thought of (Smith *et. al.*, 1995).

Chosen method of producing data

The aim of the current study was to explore the lived experience of delirium for individual participants. Interactions within the group may influence the way in which participants discuss their experiences, and may produce responses that are governed by group dynamics rather than their own lived experiences. Therefore, focus groups did not seem to be the best methodology for the study. As little is known about the lived experience of delirium after hip fracture it seems important to allow the participants to be flexible in their responses and it may be interesting to explore complex or ambiguous issues. Structured interviews appear too constrained to allow this. Semi-structured interviews, on the other hand, permit greater flexibility allowing the researcher to explore interesting topics that emerge during the interview and enabling the respondent to give a fuller picture (Smith *et al.*, 1995). Therefore, semi-structured interviews were considered the best method of eliciting information about participants' lived experiences of delirium.

Ethical Issues

Delirium in older people is an ethically sensitive area and much consideration went into the ethical implications of the study.

Capacity to give informed consent

A person is considered to lack capacity if he or she is unable to make a decision because of an impairment or disturbance in functioning of the mind or brain, whether this impairment or disturbance is permanent or temporary. A person is judged to be unable to make a decision if he or she is unable to understand the relevant information, including information about foreseeable consequences, and use that information as part of the decision making process. The person must be able to retain the information, but the fact that he or she may only be able to do so for a short period only does not prevent the capacity to make the decision (Department of Constitutional Affairs, 2005).

Initially I had planned to interview people while they were actively delirious. The fluctuating nature of delirium suggests that in some cases people would have the capacity to make an informed decision to participate in the study, despite being technically delirious. However, some potential participants would not have the capacity to make the decision to be interviewed. In these cases, I proposed to obtain written assent from relatives, with retrospective written consent from the participants once their delirium had resolved. Any participant who did not want to give consent at this point would then be excluded from the study and all information collected about them destroyed.

For patients with dementia, this issue was more difficult, as they may not have the capacity to make an informed decision to participate at any point. For these participants, it was suggested that written assent be sought from family members. While this is not ideal, it seemed important to not exclude this group from the study given the array of negative outcomes associated with delirium in hip fracture patients (Holmes & House, 2000b) and in patients with delirium superimposed on dementia (Fick & Foreman, 2002).

However, consultations with the Trust Data Protection Officer indicated that it would be a breach of the data protection law to include patients in the study who lacked the capacity to give informed consent at the time of interview.

The main difficulty is over the consent of the patients with delirium or dementia. It would not be legal to proceed and then get consent retrospectively. ...The fact that a patient is incapable

of giving informed consent means that there is little you can do to include them as a research subject. Legally it is not warranted to get a relative to agree on the patient's behalf. Neither would it be legal to use a person's personal data by claiming it is in the public interest or in their own best interest.

Colin Bedford (2004) Data Protection Officer, Leeds Teaching Hospitals Trust. Personal communication

A Revised Approach

The difficulty of including participants who did not have the capacity to make the decision to participate necessitated an amendment to the initial study design.

One possible way of altering the design could have been to obtain informed consent from participants on their arrival at hospital. The majority of patients become delirious after they have had surgery, and so would be able to agree to participate before having their operation. This solution has been employed by other researchers (Andersson *et al* 2002a; 2002b). However, unlike Andersson *et al* who were able to spend a large amount of time at the hospital where they were conducting research, at the time of recruiting I was limited to a maximum of four days a week (including weekends), with the possibility of evenings only for the other three days. Therefore, this was not considered a viable option.

The problem of capacity to give informed consent was resolved by only including individuals who were judged to have the capacity to make the decision to participate in the study on the criteria offered at the beginning of this section. In fact, for the majority of participants, relatives were not present at the times the researcher visited the wards (although this was frequently in the early evening and at weekends), so in practice reliance on relative assent would have made it very hard to recruit.

Confidentiality

All participants were given a number and pseudonym, and all information was recorded using this number to preserve anonymity.

Clinical screening measures were used in the study to detect delirium, depression or dementia. Individuals who were found to be in the clinical range on any of these measures were asked if this information could be shared with the medical staff to ensure the best package of care was delivered. Some participants did not agree to this, so the information was not shared.

All data about participants is stored in a secure place. At the end of the study all audio-material will be destroyed. Transcripts will be kept in a secure place for the length of time stipulated by research guidelines.

Ethical Approval

The proposal was submitted to the Local Research Ethics Committee for ethical approval. The committee initially raised some concerns about the issue of informed consent and asked for clarification of some practical aspects of the research. These issues were addressed in writing and ethical approval for the study was granted. Trust Research and Development approval was also obtained for the study. Copies of the correspondence with the ethics committee and the Research and Development department can be found in Appendix B.

Methods Used in Current Research

In this section I will describe the methods used in the research. Where appropriate I will use examples from the first case study, Mrs Amber, to illustrate the research process.

Study Design

The aims of this study are to gain an increased understanding of the lived experience of delirium in elderly hip-fracture patients, and to explore the longer-term psychological implications of this experience. This study therefore has a longitudinal design.

The first aim of the research was to explore the experiences of delirium in older people as near to the time of confusion as possible, to try to most accurately capture the lived experience of delirium.

It was anticipated that interviewing people who were actively delirious could generate responses only loosely based in reality. Although the amended research design required that participants be able to give informed consent, delirium is a fluctuating condition, and people can be quite lucid at times during a delirious episode, while at other times being markedly confused. A second group of older people in hospital following hip fracture, but who had no detectable current history of delirium, was suggested to offer additional contextual information about the general experience of hospitalisation following hip fracture in case the data from the delirious group lacked this detail. However, after analysis of the transcripts from the delirious

group it was decided that the data was sufficiently rich to focus the study on the experience of this group alone.

In addition, I was interested in the longer-term impact of delirium. The second aim of the research, therefore, was to investigate how participants made sense of their delirious experiences 3 months later, when most would have returned home, and to explore how they have interpreted their experiences and the issues these raise for them, e.g. in relation to attitudes towards future hospitalisation.

Materials

Interview Schedules

Two semi-structured interview schedules were developed in line with the research aims for use in this study (See Appendix C). The interview schedules were designed with IPA methodology in mind to ensure that the data generated from the interviews was suitable for IPA analysis.

The interview schedules were constructed bearing in mind Smith *et al.*'s (1995) recommendations to discuss more sensitive issues later in interview, once rapport has been established. For this reason, participants were initially asked to talk about relatively non-threatening topics (in the first interview asking for the story of how they came to be in hospital, in the second, asking broadly about how things have been since leaving hospital, and moving on to general recollections of hospital) before moving on to ask about their experiences of delirium.

Interview schedule 1 was developed to be used with participants shortly after reparative hip fracture surgery, while they were still in hospital. The focus of this interview was to elicit current or recent experiences, with particular reference to any unusual experiences and how these were thought about. This interview was conducted with all those who consented to participate in the study. No judgement was made prior to this interview about whether or not the participant had experienced an episode of delirium, and data from this interview was used as part of the assessment of delirium.

Interview schedule 2 was used with participants who had experienced an episode of delirium during their time in hospital three months after the initial interview. The main themes of this interview were to explore participants' reflections on their experience of hospitalisation, how they have tried to make sense of their experience of delirium, and possible impact of these experiences upon their attitudes towards future hospitalisations. Participants were also asked

whether they had had any delirious experiences since being in hospital, and questioned about what they might consider helpful to manage delirious experiences.

Assessment Materials

The main data for this research project comes from the analysis of the semi-structured interviews. Participants also completed some screening measures, to assess the presence of delirium and to obtain additional contextual information to get a fuller picture of the context in which their experiences occurred. As depression and dementia are prevalent conditions among older people in hospital following a hip fracture (Holmes & House, 2000a), it was considered important to screen for these conditions because of the impact their presence may have on the experiences reported by the participants in the study. Depression may lead to more negative interpretations and meanings being given to experiences, and participants with dementia are likely to have more difficulty recalling their experiences when interviewed. Copies of the measures can be found in Appendix D.

Delirium was assessed for in all participants at the time of the first interview using the *Delirium Rating Scale* (Trzepacz, Baker & Greenhouse, 1988). The *Delirium Rating Scale* is an observer rated scale that is based on diagnostic criteria and assesses symptoms of delirium over nine domains, including perceptual disturbance, psychomotor behaviour, lability of mood and variability of symptoms. In order to gain a comprehensive picture of an individual, information pertaining to items on the scale is collected from a range of sources, including the individual, nursing reports and nursing and medical notes. The maximum score on the DRS is 32, with a score of 10 or over indicating the presence of delirium. The *Delirium Rating Scale* has been well validated in elderly general hospital patients (Rockwood, Goodman, Flynn & Stolee, 1996).

Depression was assessed using a shortened version of the *Geriatric Depression Scale*, GDS, (Sheikh & Yesavage, 1986). The shortened GDS used is a 15 item self-report questionnaire to measure depression, covering areas such as worries, mood, memory & concentration, activity levels and attitude towards life. The maximum score on the measure is 15. Participants scoring below 5 are not judged to be depressed. Scores between 5 and 10 indicate mild depression, and scores of 11 or over indicate severe depression. The GDS has been shown to have good reliability and validity and has been used with medically ill and mild to moderately cognitively impaired older adults (Kurlowicz, 1999).

Dementia was assessed for using the *Blessed Dementia Scale*, BDS, (Blessed, Tomlinson & Roth, 1968). The BDS is comprised of two sections. In the first section a relative / person who

knows the patient well is asked about changes they have observed in the patient in last six months, including changes in performance of everyday activities, changes in habits and changes in personality / interests /drive². The six-month time frame allows established cognitive deficits to be distinguished from transitory cognitive impairment (delirium).

The second component of the *Blessed Dementia Scale* a short test covering information recall (e.g. name), memory and concentration is administered to the patient. This component of the scale was omitted, as it would be a duplication of items on the *Standardised Mini-Mental State Examination* (see below). The BDS does not use clinical cut-offs, but a score on any item suggests the presence of dementia-related difficulties.

Overall level of cognitive functioning was assessed using the *Standardised Mini Mental State Examination* (SMMSE) in order to determine functioning at the time of interview. The SMMSE is a 12 item measure of cognitive functioning, assessing short and long term memory, orientation, attention, concentration, language, praxis and graphia. The measure generates a maximum score of 30. A score of 23 or under indicates a degree of cognitive impairment. It is based on the Mini Mental State Examination (Folstein, Folstein & McHugh, 1975), but has improved inter-rater and test-retest validity (Molley, Richardson, Jyu, Lemay, Hisock & Keegan, 1998). The SMMSE has been demonstrated to be suitable for use in orthopaedic settings (Holmes & House, 2000b).

Depression and overall cognitive functioning were re-assessed using the same measures at follow-up to provide additional contextual information for the data generated by the second interview. It was assumed that the rating of dementia was unlikely to have significantly altered in the course of three months.

Additional Materials

Information sheets were developed to give details of the study to potential participants. They were encouraged to discuss participation with relatives, and were given the opportunity to ask

² In practice, the ethical requirement that participants be able to give informed consent to the study meant that most people with dementia were not able to consent to be screened for dementia. In addition, for the majority of participants no relatives were present to complete the scale. Instead, it was used as a guide to points for the researcher to be aware of, both through talking to and observing the person (over a minimum of 3 occasions) and through conversations with nursing staff and the nursing and medical notes. In the few cases where it was unclear, arrangements were made to meet a relative to complete the scale.

any questions before agreeing to participate in the study. A consent form was produced to gain written consent from participants. A follow-up information sheet was also developed and sent out with the letter inviting participants to be interviewed for a second time to remind them of the details of the study. Copies of information and consent forms can be found in Appendix E.

Pilot Study

In October 2004 the screening measures and interview schedules were piloted on 4 older people in hospital following hip fracture. This allowed me to become increasingly familiar with the screening measures and the interview format. It also helped me to develop my interviewing technique. The pilot interviews were discussed with my research supervisors, and some changes in the interview procedure made:

Interview Technique

The questions in the interview schedule were worded in a way that often elicited only yes / no answers. It was agreed that the 'questions' should be used as topic guides, allowing the participants maximum opportunity to 'tell it like it is' for them. Specific questions could be asked if a particular theme had not been mentioned, but a much more open-ended stance was employed, echoing back participant's comments to encourage them to expand on them with minimum direction from the interviewer. This is in line with recommendation for using semi-structured interviews, where *Good interview technique ... often involves a gentle nudge from the interviewer rather than being too explicit* (Smith *et al*, 1995, pg. 15).

e.g. Sample from Pilot interview 1:

R: Have you noticed any other times things being "different" in hospital?

Mrs Saffron: I didn't know I was in hospital because I didn't see anything medical – when I came around there was no-one there at all.

R: Have you seen people you didn't expect to see here?

Mrs Saffron: No – I've not seen anyone

Here, following the interview schedule too rigidly led me to miss out on interesting areas to explore. My question about seeing anyone you didn't expect to see in the hospital ignored the fact that she had just told me that when she *came round* there

was *no-one there at all*. Sticking with her theme of not knowing she was in hospital and feeling there was *no-one there at all* may have led to more understanding of her experiences and how she made sense of them.

In interviews after the pilot group, I tried to allow the emphasis to be on what the participant was telling me, rather than follow a predetermined set of questions, for example by echoing back the last statement made to encourage the participant to expand on the theme.

For example:

Mrs Amber: I think I'm queer [laughs]

R: You think you're queer

Mrs Amber: I think I'm weird. It's strange, and I haven't said anything about this to anyone

Discussion was also held about the balance between allowing participants maximum opportunity to tell their stories and keeping a focus on the experiences of hospitalisation (c.f. Smith *et al.* 1995).

Timing of screening measures

In the pilot study, the screening measures were asked before the interview. However, on reflection it appeared that the question-and-answer format of the measures may have set up expectations for the main interview as a question and answer format. To allow the interview to be as open-ended as possible, the screening measures were asked after the main interview in the actual study. This had an additional benefit of allowing a detailed exploration of the delirious symptoms during the context of the interview and this information could be used to help score the *Delirium Rating Scale*. It also meant that I was blind to the delirious state of participants during the interview. It was also decided to keep the tape recorder on during both interview and screening measures to capture as many of the individual's comments as possible.

Revision of Inclusion/exclusion criteria

The exclusion criteria were also reviewed after the pilot study, and amendments made. Initially I considered excluding participants who were found to be depressed to ensure a homogenous group. However, following the pilot interview (where one of the four was found to be depressed) it was decided that the experiences of these people was important to capture,

especially given the fact that a high proportion of older people in hospital following a hip fracture have been found to be depressed (Holmes & House 2000a). The Geriatric Depression Scale was still administered to provide background context for the individual interviews. In addition, I had originally proposed to exclude participants living outside the Leeds area due to potential difficulties in visiting them for a follow-up interview. This criterion was dropped to maximise the number of potential participants. The finalised inclusion and exclusion criteria are shown in Figure 1.

Recruitment

I visited the wards on average 3 times each week to give information about the study to potential participants. They were asked to think carefully about whether they would like to be involved in the study and to discuss this with friends or relatives if they wished. Assurance was given that their treatment would not be affected if they decided not to take part. At least 24 hours was given for people to consider whether they would like to participate.

People who agreed to take part in the study, and who were judged appropriate for the study on the basis of the inclusion / criteria (see Figure 1) were asked to sign a consent form. I explained that they were free to withdraw from the study at any time.

I wrote to participants who had agreed to be contacted again in order to arrange a convenient time and place for a follow-up interview. A copy of this letter can be found in Appendix F.

Figure 1. Inclusion / exclusion criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> ◆ <i>Older Adults (aged 65 years or over)</i> ◆ <i>Have undergone surgery for a hip fracture.</i> 	<ul style="list-style-type: none"> ◆ <i>Unable to give informed consent to participate in the study.</i> ◆ <i>Unable to be moved to a side room for the interview to take place to ensure confidentiality of responses*.</i> ◆ <i>Unable to be interviewed (including patients who are too unwell, and patients who are unable to understand or reply to the interview questions).</i>

* In practice, none of the participants took up the offer of being interviewed in a side room.

Sample size

There is no definitive answer to the issue of sample size in qualitative research. Some methodological approaches advocate continued recruitment until saturation of themes has been achieved. However, IPA does not emphasise this requirement. Smith (2004) reflects that IPA involves a detailed, nuanced analysis which can only be achieved with a small sample size, and notes that many studies have between 5 and 10 participants.

This is also in line with the guidance on sample size in qualitative research projects for doctoral theses in clinical psychology offered by Turpin *et al.*, (1997). They advise a minimum of 5 participants, but recommend a sample size of between 8 and 20 participants.

Interview Procedure

Initial Interview

Participants were interviewed while in hospital about their experiences and assessed using the screening measures. This was recorded on audiotape, and transcribed by an independent typist for later analysis.

Those who had been delirious were asked if they would mind being contacted again in three months time to arrange a follow-up interview.

Follow-up interview

I visited people who agreed to be interviewed again at their homes. The transcripts of their first interviews were reviewed prior to the second interview to identify any particular issues that may need elaborating on in the follow-up. As before, the interviews were audio-taped and transcribed for later analysis.

Analysis

Data from the semi-structured interviews were analysed using IPA. Figure 2 gives step-by-step details of this procedure.

IPA is an idiographic approach, and involves detailed analysis of individual cases before considering cross-case analysis of themes (Smith *et al.*, 1995). Therefore, each interview was analysed individually before considering similarities and differences across the group. While every effort was made to keep the cases separate in my mind and not use themes identified in other transcripts to guide my initial analysis, I was nevertheless aware of previously identified themes when I was analysing new transcripts. However, I did my best to minimise this (for

*Figure 2 – Steps of IPA analysis***IPA ANALYSIS**

STEP 1: Read through transcript to get general 'feel' for it and initial reactions noted.

STEP 2: Read transcript again, highlighting sections of interest or significance and making notes on left-hand margin

STEP 3: Leave to one side for a day so come to it with 'fresh eyes'. Read transcript through a 3rd time, adding extra notes to left hand margin for anything missed in previous reading.

STEP 4: On a separate sheet, make notes of main ideas that come to mind when not looking at transcript

STEP 5: Read transcript through a 4th time, making notes in right hand margin of emerging themes that capture left hand comments. Initial notes condensed into concise phrases capturing essence of what was found in the text.

STEP 6: Read through transcript 5th time, making sure all left hand column notes are encompassed in right hand margin.

STEP 7: Listen to tape to double check transcription, but also to check emerging analysis fits with 'voice' of participant – i.e. non-verbal elements not captured on paper transcript.

STEP 8: On a separate sheet, pull out all right hand themes, with evidence to create a master list of themes. Check all left and right hand themes accounted for.

STEP 9: Read transcript again and review master theme list looking for connections between themes and clustering themes appropriately, checking back to original transcripts to make sure fits with what participant said.

STEP 10: Create a detailed pen-portrait with all themes and supporting quotes

STEP 11: Conduct same process with follow-up interview

STEP 12: Compare themes of initial and follow-up interviews, looking for similarities, differences and developments in thinking over 3-month period.

STEP 13: Conduct same process with each interview in turn

STEP 14: Compare themes of all participants to look for similarities and differences.

example only considering the analysis for one case on a given day), and only moved to explicitly look for similarities and differences at the last stage of analysis.

Initially the transcript was read through several times to allow me to become familiar with the account. Re-reading is important, as each new reading is likely to offer new insights (Smith *et al.*, 1999). Interesting or significant aspects of the transcript were highlighted and notes made in the left-hand margin on details such as use of language, associations that come to mind, similarities or contradictions with other parts of the text or preliminary interpretations. The right-hand column was used to note emerging theme titles using key words that try to capture the quality of the data (c.f. Smith *et al.*, 1999). The main themes were then written in a separate sheet and connections between themes looked for to create a master list of themes, with associated sub-themes. Each theme was carefully checked against the original transcript to ensure that it fitted with what the participant actually said. Follow-up transcripts were analysed in the same way. This process was then repeated for each participant. Finally, the Master Theme list for all participants were looked at together to look for overarching group themes. Figures 3-5 provide examples of the analytical process.

Figure 3 Example of IPA coding – Mrs Amber

<i>Becoming more active</i>	one day I swung myself around and I got myself up, with a bit of help, of course, and	<i>Balance between independence and dependence</i>
<i>Emphasising she did it herself, but recognising she needs help</i>	swing my legs round and get them going downwards. Ah – I felt like a different person,	
<i>Feeling better for being active / taking control</i>	and the nurses, they couldn't believe I've done it but then I had to stand up of course and I had	
<i>Impressing nurses with her actions</i>	that thing to stand up with but I couldn't stand on this leg that was operated on, and the other	
<i>Struggle to regain independence</i>	leg wasn't so strong either cos I hadn't used it for such a long while and I got myself from my bed facing that way to this chair and I've been	<i>Regaining identity as independent person</i>
<i>Feeling more like herself</i>	much better, I mean in myself, feeling like well, more or less.	

Figure 4 Sample memo 1 – creating codes and themes

Thoughts on coding section for Mrs Amber

active Vs passive – feels better at being able to take active role.

Why is it important to her to have an active role?

Asserting her independence / regaining identity as an independent person? This fits with other comments she makes (e.g. *I'm independent and I hate being dependent on other people*)

But, she isn't fully independent – although she initially states twice she did it herself *I swung myself around and I got myself up*, she also acknowledges she needs help *with a bit of help, of course*.

This also fits with things she says later in interview (e.g. *you can't do anything because even to get up to walk, I couldn't reach the frame to walk with anyhow, so if I can just get a nurse to walk those few steps or be there while I do it, I'm alright*).

So, final coding is that this section illustrates the struggle to find a new balance between dependence and independence – wants to be independent, but recognises she needs help. This seems to fit with lots of her other comments and builds the picture that this is a significant issue for her.

Figure 5 Sample Memo 2 – group themes

Dependence

Should this be a group theme?

Several participants talk about this, but all relate to it in a slightly different way – e.g. Mrs Amber trying to find a new balance between dependence and independence / Mrs Rose recognises needs help, but uncertain her needs will be met. For both, delirium seems to have had an impact. Mr Black talks about loss of independence in adjusting to old age, but he does not talk about delirium impacting on this.

Maybe discuss it as a group theme, but be careful to highlight individuality of responses to issues of dependence.

The original transcript was re-read at each stage of the analysis to ensure that the emerging themes fit with the original data. In order to further check the accuracy of interpretations, after initial themes had been identified, I listened to the audio-tape of the interview to check that the themes identified from the verbal data of the transcripts fitted with the non-verbal data, such as emotion and tone of voice of the participant during the interview.

The Researcher

Qualitative analysis cannot be entirely objective as it necessarily involves the researcher's own interpretation of what is said by participants. To enable a reader to judge the accuracy of interpretations made, it is good practice for a researcher to disclose as much of their personal standpoint with regards to the research as possible. As Elliott *et al.* (1999) note, the *disclosure of values and assumptions helps readers to interpret the researchers' data and understanding of them, and to consider possible alternatives* (pg.221). I will therefore give a summary of my background, expectations for the research and theoretical preferences.

My experiences of delirium, both in witnessing others with delirium while working as a nursing auxiliary, and my own experience while in India have made me curious about how people make sense of these unusual experiences. Therefore I welcomed the opportunity to study this area in my research for the Doctor of Clinical Psychology degree.

My Grandma has been diagnosed with Alzheimer's Disease and at times struggles to make sense of the world around her.

I am becoming increasingly interested in psychodynamic approaches in my clinical work, and value the attention to interpersonal processes psychodynamic therapy encourages, although my knowledge of psychodynamic approaches is limited.

Quality Standards in Qualitative Research

With the increasing popularity of qualitative research several authors have considered the standards by which qualitative methodologies can be evaluated. The guidelines suggested by Elliot *et al.*, (1999) and Stiles (1993) have been used to guide this study. Through outlining my own experience of delirium and discussing the background of the researcher, I have tried to *disclose my orientation and own my perspective* on the research. The process of analysis outlined in this chapter, involving multiple reading of the transcripts illustrates my *engagement with the material*. In discussing examples of the analysis of data I have offered some description of *the internal processes of investigation* and provided some *grounding in examples*. These will be further addressed in the results and discussion sections. The issues of

situating the sample (giving details of the participants) and *coherence* will also be considered in the results and discussion sections.

Checking the credibility of the interpretations made is another important quality standard in qualitative research (Elliot *et al.*, 1999; Stiles, 1993). This can be accomplished in a number of ways. To assess the trustworthiness of my interpretations in this study, I employed four credibility checks:

1. I attended a monthly IPA study group with peer researchers to discuss methodological issues. This included the group analysing a section of one transcript. Although new insights were offered about ways in which the data could be interpreted, largely suggestions by the group were in line with my own interpretations.
2. A transcript was randomly selected and independently analysed by a peer reviewer. Areas where our interpretations did not entirely match were discussed and consensus achieved.

These credibility checks were completed early on in the analytic process, and insights from these discussions used to inform further analysis. The two other checks utilised were:

3. At points where I was uncertain of the credibility of interpretations, these were discussed with a peer researcher also using IPA to minimise the risk of bias and over-interpretation of the data.
4. Anonymised data from one transcript (including original transcripts, left and right hand codings, main themes and pen-portrait) were submitted to another independent reviewer. This reviewer verified that interpretations were grounded in the data and appeared to be a fair representation of the participant. The first transcript was selected for this process in order to check the interpretations before continuing to analyse further transcripts.

Overview of Design

The aims of this study are to investigate the lived experience of delirium in older people following surgery for hip fracture to explore how people made sense of their experiences, both during hospitalisation and at three-month follow-up, additionally looking at the potential impact these experiences may have on thoughts about future hospitalisation. In this chapter I began by considering the theoretical aspects of methodology suitable for addressing this issue. I considered the ethical issues of studying this population and then detailed the methods chosen to address these aims.

RESULTS

The results are presented in five sections. I will begin by providing details of the participants of the study. I will then discuss the results of the first interview, initially offering a detailed case-by-case analysis before moving on to look at key issues that emerge across the group. Similarly, a case-by-case analysis of the follow-up interview is provided, followed by consideration of group themes for participants, including a comparison with themes from the first interview. Finally I will consider issues arising from the interview process.

Participants

Details of the participants in this study are outlined below. Tables 1 and 2 present additional contextual information for the initial and follow-up interviews. Further information is provided in the case-by-case analysis.

Recruitment for the study took place between October 2004 and March 2005 on two orthopaedic trauma wards. During this time an estimated 160 older people³ with a hip fracture were admitted to the wards.

63 older people (14 men, 49 women) in hospital following a hip fracture were approached and given information about the study.

18 (2 men and 7 women from each ward) fulfilled the criteria for the study and agreed to participate. The first 4 participants were assigned to the pilot group. Of the remaining 14 participants, 4 had not experienced any detectable symptoms of delirium; 1 experienced delirium prior to hospital admission⁴.

Of the 45 who did not participate, 25 declined⁵; 8 were not available at time of interview⁶; 12 did not appear to have the capacity to consent.

³ Estimate based on figures from Holmes & House (2000b)

⁴ This participant was excluded as her experiences occurred before hospitalisation.

⁵ People who declined to participate frequently did not give a reason. Those that did specified that they felt too tired or wanted to concentrate on getting better.

⁶ Reasons for not being available to be interviewed included discharged, had visitors with them or were off the ward for investigations e.g. x-ray.

Tables 1 & 2 Characteristics of Participants

Table 1 – Details of participants at Interview 1.

	Age	Days since op.	Delirium (DRS)	Cognitive (MMSE)	Depression (GDS)	Dementia (BDS)	Ongoing symptoms?	Nurses aware?
Mrs Amber	81	3 days	14	28*	4	0	√	X
Mrs Blue	88	4 days	10	25	7	0	√	X
Mr Black	78	8 days	14	26	0	0	?	√
Mr Brown	77	6 days	11	19	4	0	√	X
Mrs Green	70	1 day	12	28	3	0	?	X
Mrs Grey	88	6 days	14	23*	5	4 ½ **	√	√
Mrs Plum	88	6 days	19	23	6	0	√	√
Mrs Rose	91	11 days	20	27	2	0	X	√
Mr White	89	12 days	21	17	7	0	√	√

* pro-rated as unable to complete drawing task due to physical restrictions ** completed at follow-up interview as relative not present at initial interview

Table 2 Details of participants at Follow-up Interview

	Follow-up interview?	Reason for declining follow-up interview	Cognitive (MMSE)	Depression (GDS)
Mrs Amber	√	N/A	30	3
Mrs Blue	X	Not arranged	N/A	N/A
Mr Black	√	N/A	29	2
Mr Brown	X	Died	N/A	N/A
Mrs Green	√	N/A	27	4
Mrs Grey	√	N/A	26	6
Mrs Plum	X	Did not want to talk about stressful hospital experience	N/A	N/A
Mrs Rose	X	Currently moving to residential care	N/A	N/A
Mr White	X	Died	N/A	N/A

Key to Tables

Scores in red fall within clinical range. NB. All red scores on GDS fall within the *mild depression* range

√ = yes

X = no

? = unclear

Nine older people were included in the study. Four of these agreed to a follow-up interview.

Although details on ethnicity were not specifically obtained, all participants appeared to be of White British origin. In fact, all patients approached with details of the study appeared to be of this ethnic origin. This is consistent with the population distribution in the locality of the hospital, where other ethnic groups form only a small percentage of the elderly population.

Initial Interviews

In this section I will discuss the key themes arising for participants on a case-by-case basis before moving on to look at key issues arising across the group.

Case-By-Case Analysis

In order to allow the reader to gain a clear sense of the participants in this study I will offer a case-by-case analysis of the main issues for each participant. In each case I will give some additional contextual information, including the current situation of the individual, comments on the context of the interview, and a summary of their delirious experiences. I will then consider the key themes arising for each person.

Case 1 – Mrs Amber

Situation

Mrs Amber is a lady with multiple medical problems, including arthritis, diabetes, asthma and recently the doctors found she has breast cancer. She has also had a heart by-pass in the past. She lives alone.

The Delirium

Mrs Amber reported 2 experiences that were 'out of the ordinary'. On one occasion she saw the cast of *Eastenders* lined up in the bay opposite her bed. She reported being able to hear what they were saying, as if they were performing a play. The other unusual experience Mrs Amber described was a sense of déjà vu when watching television. For every programme she watched she was certain she had seen it before and knew exactly what would happen next (e.g. who would answer the next question on a quiz show, or who would be out next). This was

more than the feeling that the show was a repeat of something she had seen some time before. This experience lasted several days (although it had resolved by the time she left hospital), and often occurred when everything else around her seemed perfectly normal.

Context of Interview

Mrs Amber tired quickly on the day I started the first interview with her, and so I continued the interview the following day when she appeared considerably brighter. She asked me not to inform nursing staff about her experiences.

Key Theme: Trying to make sense of delirious experiences

Mrs Amber appeared to struggle to make sense of her experiences of delirium, describing her experiences as 'weird' and 'so strange' and reflected *I still can't weigh it up*. She appeared uncertain of the reality of her experiences, fluctuating between talking about them with certainty *'I'm sure I have seen it before'* and using more tentative language, *'it's as if I've seen the thing before'*.

To try to make sense of her experience, Mrs Amber tried to find explanations that fitted with her 'ordinary' experiences, for example modern technology, which she also found *strange*.

I just thought it was something that was new, I mean I'm not well up on televisions and things like that, I'm not greatly interested in televisions but I thought it was something new. I mean like all these things, emails and all the other, I mean I don't have to deal with them and I don't deal with them and it's all a bit strange.

She also tried to find explanations within a medical context, noting that her experience of seeing *Eastenders* was shortly after her operation and linking her experiences to the effects of medication

I think it's just one of those drugs and things, it could upset a lot of things in your body, couldn't it, including your brain.

However, Mrs Amber did not appear certain of her medical explanations, commenting on her lack of previous hospital experience to be able to judge her current experiences

I don't know, you see I've not really been in hospital for any length of time, you know, I haven't experienced much like this before and I don't know

Mrs Amber also tried to check out her experiences with others around her to see if she was the only one who noticed them. However, she did not feel reassured by the responses she got

Well I said to her, I said oh they are repeating these programmes, she said yes they do keep doing that don't they, but I think she was, she was not being sincere, just like you might say, good heavens I've seen this a year or two ago, you know

Key Theme: Unease at delirious experiences

Mrs Amber appeared uneasy about her delirious experiences, and tried to minimise what had happened, and frequently laughed when talking about her experiences

I think its stupid [laughs] I mean, it's just another silly thing

However, she did not seem able to dismiss her experience, and fluctuated between externalising the experience (*It's strange*) and internalising the experience as a reflection on herself (*I think I'm weird*).

Key Theme – Concerns about mental health

Mrs Amber appeared concerned about what her experiences meant about the state of her mind, commenting *I think I'm weird* and *I think I'm queer*. She was also concerned that other people might think she was *crackers*. In the context of her recent medical experiences where *everything they look at there's something else wrong* Mrs Amber was clear that she did not want anyone looking for problems with her mind.

I have enough going on without anybody trying to find out what's wrong with my mind because my mind is fully functional... My body's old, but my brain's still active.

Key Theme – Finding a new balance between dependence and independence

Mrs Amber stressed the importance to her of being independent *I'm independent and I hate being dependent on other people* and was keen to be as independent as possible while in hospital. However, she recognised that she was reliant on help from others to be able to achieve more independence

you can't do anything because even to get up and walk, I couldn't reach the frame to walk with anyhow and so if I can just get the nurse to just walk those few steps or be

there while I do it, I'm alright. So I'm going to insist on that, you know, because I feel better when I'm stood up for a little while

Despite recognising that she needed help, Mrs Amber appeared very frustrated at her lack of independence, and her need to rely on others to do things for her - *I get so frustrated I can't do things you know*. This frustration was exacerbated by the fact that nursing staff were often too busy to give her the support she needed to be more active.

I feel I'm just sat here and, I don't know, not doing, but they're so busy they haven't time to keep coming to individuals you know

Given Mrs Amber's frustration at being dependent, it seems possible that her concerns about finding problems with her mind may have implications for her about her continuing independence.

Case 2 - Mrs Blue

Situation

Mrs Blue lives in sheltered accommodation.

The Delirium

Mrs Blue reported that at times she was unsure of her location when she returned to the ward after leaving it, e.g. for x-rays. Mrs Blue also described waking up one night and thinking that she could see 6 men *taking half the kitchen out*. Mrs Blue appeared to find this quite frightening, and was relieved the next day when she realised everything was all right.

Context of Interview

Despite being keen to talk to me, Mrs Blue appeared distractible throughout the interview. This is likely to have been a symptom of her delirium. Mrs Blue's distractibility made it difficult to interview her properly and so information from her interview was limited.

Key Theme – Trying to make sense of delirious experiences

When she awoke in the night to find men *taking half the kitchen out*, Mrs Blue reported that she had tried to understand what was going on by asking those around her. However, she did not receive any satisfactory explanations

I just laid there cos I couldn't understand it, I kept asking and they'd say "shh", and all that sort of thing. Didn't get much further on with it

After the delirious episode had past, Mrs Blue was able to reflect on her experience. She attributed the cause of her unusual experience to being *half asleep* which made her misinterpret events on the ward (namely a patient being brought in on a trolley).

Mrs Blue also seemed to be trying to make sense of the content of her delirium, associating it with recent break-ins in her neighbourhood. She reflected that she was not usually worried about break ins, but reasoned she must have been to have thought about it that night

I'm not nervous about that kind of thing, but I must have been at some times

Key Theme – Unease at delirious experience

Mrs Blue appeared quite wary about discussing the fact that she had been confused. When I initially approached her, Mrs Blue said that she had felt that she had been confused at times. However, when I returned with the tape-recorder, she appeared very hesitant about discussing her experiences with me. Initially Mrs Blue denied any unusual experiences, stressing that *It's all very good, marvellous, yes. Late at night, very normal.* However, she later reported that it was during the night that her delirious experience had occurred.

When I asked her about her comment that she had been a bit confused while in hospital, she dismissed this, explaining that she sometimes gets confused when talking to her daughter as she talks so quickly. However, as the interview progressed, Mrs Blue acknowledged that she had at times been uncertain of where she was when returning to the ward after x-rays etc., and then went on to describe the experience where she thought the men were taking out the kitchen.

To try to assure herself that her experience was normal, Mrs Blue also tried to check out with another patient if she had also been confused by the night's events, asking the next day *did you wonder what was up?* In reflecting on what happened, she appeared keen to dismiss the experience and offer normalising explanations

I don't know, but yeah, you take it in your stride, don't you. You miss you sleep, you are wondering what aren't you?

Key Theme – Relief at being cared for

The experience of falling and fracturing her hip appeared to have been quite shocking and frightening for Mrs Blue.

I knew I'd gone with a bang, what a bang, and I was just stunned.

Mrs Blue described how she struggled to get help, but that she *somehow managed* to move to activate her alarm. However, she reported feeling relieved at getting help and support. She described feeling very well looked after, which seemed in contrast to her initial struggle to get help

They're here to help you; they're very good. Yeah. Don't know what we'd do without them, yep.

However, despite feeling supported and cared for while in hospital, this support was not evident during her delirious experience with the nurses only saying *shh* when she tried to ask them what was happening while she was delirious.

Case 3 – Mr Black**Situation**

Mr Black had emigrated to Spain with his wife 2 years ago. However, they decided to return to England and settle in a retirement complex. It was as he was leaving the plane that Mr Black fell and fractured his hip. Mr Black informed me that his hip surgery was the 9th operation he had undergone, and in addition has osteoporosis.

The Delirium

Mr Black was vague about details of his delirious experiences. He reported feeling unsure of where he was on first coming round from the anaesthetic, and initially commented that he was *seeing things*, although denied any delirious experiences later in the interview. Nursing staff reported that he was very agitated on returning from the operating theatre. The Orthogeriatrician independently noted that Mr Black had been delirious.

Context of Interview

Mr Black spent much of the time talking about things other than his hospital experience – in fact we talked about pretty much everything from politics to the youth of today. He was very talkative and gave detailed responses to all screening measures.

Key Theme: Unease about delirious experiences

Mr Black did not appear comfortable with the idea that he had been delirious, and fluctuated between acknowledging that he was *not right* immediately after his operation, and denying any unusual experiences. Initially Mr Black commented *I keep seeing things*, but later denied that this was the case stating *not likely, no*. He also appeared to give contradictory information at times, for example stating that it was only one occasion (when he initially returned from theatre) that he was unsure of where he was, but then commenting that the effects of the anaesthetic lasted for 4 days

Just that once, that's right. Oh no, no problem at all, never has been. I mean anaesthetic must have taken about four days to wear off as it is so you know you're not right for about 4 days all together

Mr Black appeared to try to make light of the discussion about delirious experiences. For example, when I asked him if he thought he had seen things that afterwards he thought may not have been there, or may have been something else, Mr Black commented

No, no. Nothing like that – pink elephants and all that stuff, not likely, no. I know people have that, not likely no. [laughing]

Mr Black appeared to want to distance himself from the idea that he may have been delirious. He commented that he did not dream, and was either awake or asleep suggesting no possibility of being in a state that was not either fully conscious or fully unconscious

My mind, I'm either awake or asleep, far as I'm concerned I am and that's it [laughs]

One of the most salient features of Mr Black's discourse was his way of polarising experiences and people. He frequently described things in terms of contrasts, for example the effect that *bad people* have on *people who are decent*. He appeared keen to present himself as a 'good' patient, contrasting himself favourably with other patients. When I initially asked him if he had had any 'unusual' experiences, he immediately spoke of another patient who was *crazy* and being awkward for nursing staff. This was in contrast to how Mr Black described himself on

returning to the ward after theatre *I was quite, almost oblivious really to what was going on* (although the nurse who had collected him from theatre informed me that Mr Black was in fact very agitated at the time).

In talking about people with delirium that he had witnessed, Mr Black appeared uncertain about whether they could be held responsible for their actions.

I mean I don't know if it's a thing he couldn't help, but he came over and been awkward and I thought poor girl looking after him like that.

Key Theme: Identity in the past

Mr Black spent much of the interview talking about the past, which he referred to as *the good times*, a time when he was still actively employed. He described himself as a hard worker, and commented that he has always *enjoyed what I've done*.

Key Theme: Feeling cared for

Mr Black spoke very highly of the care he received while in hospital, and this appeared to be one of the most important factors of his hospital experience.

just day by day, night by night care. They've been you know the best as it could be as far as I'm concerned, there's been no neglect at all, I've always been attended to

Case 4 – Mr Brown

Situation

Mr Brown had terminal cancer, and fell while attending an appointment at a local hospital. On the way to the LGI the ambulance was involved in an accident. Mr Brown did not sustain any further injuries, but his wife, who was travelling with him in the ambulance, broke her rib.

The Delirium

Mr Brown reported being confused about much of what happened after his arrival at hospital. I observed Mr Brown to be suspicious of the paracetamol offered to him and he refused to take it. He said he had never felt suspicious about medication before, it was only since he operation that he had felt uneasy about taking medication. Mr Brown described his suspicions and confusion as *vague feelings*.

Context of the Interview

If I had not observed Mr Brown's suspicion about medication, I suspect medical staff would have been unaware of this symptom of delirium. He was happy for me to share this information with them.

Key Theme: Resignation to illness

Mr Brown appeared to live in a world dominated by hospitals and illness. Even the friendships Mr Brown talked about were in the context of illness, those who had undergone similar treatments for cancer. Being in hospital had become *a way of life that I've become used to*, but one that he seemed weary of.

This goes on and on and on as you probably realise

Mr Brown appeared resigned to whatever happened to him. In talking about his experience as a patient, Mr Brown appeared to adopt a passive stance, and feel treated as a product rather than as a person

There were 2 ambulance men over, waiting to unload people at Cookridge so I was picked up and dealt with by the hospital staff at Cookridge

He commented that he is *quite resigned to the fact that I am going to die of cancer. Simple as that.*

Mr Brown appeared unsettled by the vagueness of his experiences, which he felt was in contrast with the normal clarity and accuracy of his experiences. He commented that he felt worried about his disorientation in the mornings *Because I'm normally fairly accurate with what I used to be thinking and get it down and documented, but I'm not saying now, unfortunately.*

However, Mr Brown's resignation to whatever happens seemed evident in his thinking about these experiences of disorientation and his suspicion about medication. He had no thoughts or explanations for why he had these experiences and did not appear interested in finding an explanation, simply stating *it's just one of those odd things.*

Case 5 – Mrs Green

Situation

Mrs Green lives with her husband and adult son. Her husband has dementia, and Mrs Green is his main carer. Her son is unable to work following an accident. He has had three hip replacement operations.

The Delirium

Mrs Green reported two unusual experiences. On first coming back to the ward from theatre she thought that there were people lined up on chairs waiting to go in to an appointment. She did not want to look at them in case they noticed her and spread misinformation about her around her local area. The second unusual experience she reported was waking up in the night and being unsure where she was, but thinking that there were dolls houses opposite her and that the furniture had been moved around.

Context of Interview

Mrs Green was a very sociable person, and seemed pleased to talk to me on both occasions that I saw her. Mrs Green asked me not to inform the medical staff about her delirious symptoms.

Key Theme: Trying to make sense of delirious experiences

In reflecting on her experiences, Mrs Green tried to understand why things might have seemed different to how they were in reality. The fact that she thought she saw people immediately after her surgery helped her to connect her experience with her anaesthetic *I mean I'd had that thing, you know, that injection and that*. Mrs Green also offered an explanation for her unusual experiences in terms of her positioning on her bed, *with being laid like that, flat*. Similarly, before describing her experience of seeing a dolls house she noted that she had slept with her pillow up.

Mrs Green also looked for explanations for the content of her delirium. She primarily noted environmental factors which could explain the unusual things she noticed. For example, she reflected that the people she saw on chairs could have been a memory from waiting to go into theatre which had been transposed.

And I mean it might be that I saw it downstairs where they was waiting to go into x-rays...And then when I've come in this door I've thought I was still with them you know

She also made links with past experience of having a dolls house as a child and wondered if that had triggered her illusion.

I mean we always had dolls houses when we were kids

Key Theme: Feeling uneasy about delirious experiences

Mrs Green appeared somewhat uncomfortable discussing her unusual experiences with me, and seemed keen to minimise them, often laughing as she talked about them.

What the hell have they put here while I've been asleep? [laughing]... But it was now!

In relating her experiences, she immediately offered explanations to try to dismiss her experiences. However, the number of simultaneous explanations she offered suggests that she may not have been entirely satisfied with them.

And I thought and I don't know whether there are curtains at the back of those, you know, I don't know whether these windows ... it just looked like a little dolls, a little dolls house you know, and I thought My God! But it looked so small being laid down. But I think it's the roof that does it

Key Theme: Concerns about others perceptions of her Mental Health

Mrs Green had not talked about her delirious experiences to anyone other than me. She appeared to be concerned how others would view her mental health if she shared her experiences with them, stating *I don't want them thinking I've gone potty [laughing]*.

Key Theme: Medical Staff as Experts

Mrs Green reported feeling well cared for in hospital, and commented *honestly, it was lovely*. She appeared to see medical staff as experts, and seemed happy to allow them to make decisions for her

I think it wants to come off this but I'm not taking it off, they can take it off

However, she was impressed that the staff tried to include her in decisions, talked to her *so you understand what they're talking about*.

They come round with tablets and that, they don't give you them like that you know, do you want some pain killers, do you want this, it's you that they're asking you know, not

like they used to be put em down there you know, whether you wanted them or not you'd to take the damn things.

they've all been so nice, not a bit like you know teachers or anything,

Despite this open communication with her, Mrs Green still felt it was important to present herself to staff in the 'right' way, commenting that she felt being *so frightened of answering in the wrong*. She was adamant that she did not want the doctors to know about her unusual experiences.

Key Theme: Identity as Care-giver

Mrs Green's role as caregiver was a prominent feature of her conversation. She not only talked about looking after her husband, but also tried to look after others while in hospital, for example the lady in the bed next to her who had dementia and was frequently confused.

She got really worked up, you know...cos I'd see that with my husband, so I thought right, I'll have a go, so I says sit down...get into bed and have a sleep, your husband will come and you'll be a lot better and she did do

Mrs Green appeared concerned about the impact her delirious experiences might have on her role as caregiver. When I first met her, she stated *I'm not confused. It's my husband who's confused* and said she needed to get better so she could go home to look after him.

Case 6 – Mrs Grey

Situation

Mrs Grey obtained a BDS score of 4 ½, suggesting she is in the early stages of dementia. She had recently moved to live with her daughter.

The Delirium

After her operation Mrs Grey was observed by her family and by nursing staff to seem disconnected from reality. She sat reciting the alphabet much of the time. Mrs Grey could not recall this. When I saw Mrs Grey following my interview with her she recounted another episode of delirium the previous night where she had thought that the red flowers by her bed looked like bed-socks, and everything appeared *flat*. She also reported thinking a film crew had come onto the ward.

Context of Interview

Mrs Grey seemed to put me in an expert role, and asked me questions about her care and my opinions about her ability to manage. At times Mrs Grey appeared to be looking for the 'right' answer to my questions.

Key Theme: Trying to make sense of the world

Although Mrs Grey could recall some details of her recent experiences with clarity, for example the details of her fall, in both interviews she appeared to be trying to make sense of her situation. For example, recognising an emotion, but initially being unable to locate the reason for it

I'm a little upset at them over something – oh, I'm reading, I was reading, yes. I want to read in bed, yes so that's, no it's fine except that I have to sit here and it's cold in the corner and read and they won't let me read in bed so that's that

She used a number of strategies to help her understand her situation, including asking me for information, trying to use past experiences to compare her current situation with, and deduction (for example when I asked her what year this is, she tried to calculate it from knowing her age and the year in which she was born). Mrs Grey did not appear concerned about her struggle to remember recent events, and normalised her experience commenting *I wouldn't say I remember everything here, how can you?*

Mrs Grey could not remember reciting the alphabet and this made it difficult for her to understand it. She appeared uncertain of the reliability of other's accounts of her behaviour and switched between attributing the confusion to herself or to her daughter.

she says you were saying the alphabet, I says I wasn't... I think there's one of us daft here [laughing]

Why was I doing that? I must be daft

Mrs Grey tried to make sense of her behaviour while delirious by placing it in a context she understood. She associated her recitation of the alphabet with a Christmas party game, but was surprised that it had occurred while she was in hospital. To help her understand this, she

requested additional contextual information, asking *where did I say this alphabet? and was I in bed or out of bed?*

Mrs Grey's attitude to her delirious experiences appeared similar to her attitude to everyday experiences – both appeared to be a bit incomprehensible at times. The uncertainty around her delirious experiences appeared no more or less than for much of her everyday life. However, she seemed surprised about the interest other people (myself and her daughter) had shown in her delirious behaviour, asking *is it a crime?*

Case 7 – Mrs Plum

Situation

Mrs Plum lives alone but has a support worker who comes daily to deliver her meals. Mrs Plum reported that one of the frustrating things she found about her hospitalisation was that being in Leeds made it difficult for her friends to visit. Despite this, she seemed to be visited regularly by friends and family.

Delirious Experiences

Mrs Plum reported several *horrible dreams* while she was in hospital. One experience that lasted several days was that some people were reporting things about her and were going to broadcast these on television and at cinemas with a photograph of her explaining she was a bad person and telling people not to talk to her. She felt she should not talk to them and had asked her son-in-law to get a lawyer for her to challenge the claims she thought were being made about her in the media. Mrs Plum also talked about other *dreams*, for example thinking there was a war going on in the ward.

Context of Interview

When I first met Mrs Plum she was clearly delirious and looked dishevelled. She told me that people were saying she was a murderer and asked if I had seen the TV reports about her. As she was clearly unable to consent to participate in the study, I returned to the ward a few days later by which time her delirium appeared to have largely resolved. She appeared well presented and lucid and was able to understand the details of the study. Mrs Plum asked me not to tell the medical staff about her experiences, but they were already aware of her delirium.

Key Theme: Trying to make sense of delirious experiences

Mrs Plum's experience of being in hospital seemed to be characterised by her delirious experiences. She made little reference to her hip fracture or the ward environment even when directly asked about these. There was a marked contrast between her poor recollection of the factors that brought her into hospital and her more vivid recollection of her delirious experiences.

I says where am I? They says Leeds Infirmary [laughing]. I couldn't equate it at all, what I'd done I don't remember at all. And then I you know, had horrible dreams

Mrs Plum described feeling unsure at times of what was real and what was a *dream*, observing *it was a dream of what actually happened, but I didn't realise*. The association with dreams appeared to be a way of trying to make sense of her experiences, likening them to an everyday experience. However, this description of her delirium as *dreams* did not seem to quite fit with her everyday experience, and she commented *I've never had a dream like it*.

When thinking about the reason for having *peculiar dreams*, Mrs Plum reflected that she may have banged her head when she fell, although she does not have a clear recollection of this

Well, I think they're peculiar dreams and why I had them, and all I can think is, and of course I bumped my head at the same time and then I fell down,

Although she seemed to have an explanation for the cause of her *peculiar dreams*, Mrs Plum struggled to understand the content of her dreams, and frequently wondered about them

It was another dream, yeah. So why I had that one I don't know [laughs]

Mrs Plum noted that her relative's had seemed uncertain about what was wrong with her while delirious, but did not specify what she thought they were wondering about.

they looked at one another and then decided that I was, I wasn't [laughing],

Key Theme: Unease about delirious experiences

Although Mrs Plum discussed her *dreams* with me without hesitation, she appeared uneasy about her experiences and frequently laughed in a way incongruous to the emotion being expressed by her words. It seemed as if she was masking her unease at her experiences by laughing, and therefore minimising them in some way.

No, it was going to be on 6 months every day it was going to be on television, going all around the country and nobody had to talk to me [laughs]

During the interview, Mrs Plum appeared to try to engage me in ways to allow her to minimise and normalise her experiences, making comments such as *it was silly, wasn't it really?* and *They are funny dreams. Do you have funny dreams?*

Mrs Plum seemed to want to distance herself from the experiences, reflecting *they're funny, aren't they, these dreams. Cos I mean it had nothing to do with me.* She also appeared to want to locate her experiences in the past, as something that was over and did not need to be considered again, saying *I reckon it were - they've gone now, they've gone.* However, she did not appear able to leave her experiences behind. Throughout the conversation it was clear she still felt overwhelmed by them, and she noted that her last *dream* had been that morning.

Case 8 – Mrs Rose

Situation

Mrs Rose lives alone, but has family living fairly locally. In addition to her hip fracture, she has had arthritis in her knees for several years.

The Delirium

Mrs Rose reported that her 'unusual' experiences had lasted for 3 days and involved several frightening delusions, hallucinations and visual illusions. These included seeing the beds opposite her move to underneath her and she became convinced that there was a drop where the floor should be. Mrs Rose also talked about being confused about her location, at one point she believed she was at her GP surgery, another occasion she thought that she had been taken to a family house, and at other times she thought that she was in Tenerife. Throughout these experiences Mrs Rose reported believing that someone was trying to kill her. She also reported believing she could hear her husband's shouts as he was being killed.

Context of Interview

Mrs Rose appeared relieved to talk to me about her experiences, and at times appeared to be looking for me to validate her experience, for example asking *It's frightening, isn't it love?*

Key Theme: Trying to make sense of delirious experience

On meeting Mrs Rose she immediately started talking about her frightening delirious experiences. These seemed to be the most salient part of her experience in hospital and were clearly very vivid, and very frightening memories that she could not forget

Well I still think about it and get frightened

In her descriptions of her experiences she frequently moved from describing one experience into describing another, creating the sense that the experiences were still muddled in her mind. There were some experiences whose reality Mrs Rose was still uncertain about

He says "Mrs Rose, you're alright, it's part of Leeds Infirmary". Well I still don't believe it.

Mrs Rose's descriptions of her experiences suggest that while she was delirious she felt caught between conflicting realities, what she believed to be true was frequently in conflict with what nursing staff were asking her to do.

But it was very frightening love, that was the worse thing love, seeing them disappear and being told that I could step out of bed when I knew I couldn't

To try to understand her experiences, Mrs Rose looked for explanations for her for example looking for environmental features that could have been misinterpreted in her delirious state.

I can still see her up there, with this thing in her hand making the bed, I says that's, I suppose that's what they do to make the bed go, the side go up and down, up and down you see, to get them out but it looked to me as though she was trying to do something to me because it went on for so long

Mrs Rose was the only person I interviewed who reported being given an explanation for her unusual experiences, namely that they were caused by the anaesthetic. Mrs Rose mentioned this explanation several times, but each time accredited it to the nurse who had told her rather than owning it as her own explanation and she did not appear entirely convinced by it

Well all I can think about love is that he said it was the anaesthetic. I mean, I've never gone through anything like that before

Key Theme: Unease at delirious experiences

Mrs Rose appeared uneasy about her delirious experiences, and frequently laughed while discussing her experiences with me in a way that seemed incongruous with what she was talking about.

[laughing] It was a terrible experience because you can't get it out of your mind

At times Mrs Rose seemed to try to minimise her experiences in talking to me, and encourage me to dismiss her experiences with her, for example commenting *I do think it's daft now, yeah. Well it was, wasn't it?* However, at other times she appeared to be looking for validation of her experiences, asking me *would you have been frightened?*

Mrs Rose appeared to want to distance herself from the experience, and leave it in the past, stating several times that it had lasted 3 days and *that was the end of that*. However, she seemed unable to forget her experience.

Key Theme: Reflections on mental state

Mrs Rose offered negative reflections on herself for her delirious experiences, and referred to herself as *daft* and *a fool*. She had not talked to her visitors about her experiences, reflecting *they might think I'm barmy...I think they'd be right*.

Key Theme: Feeling Invalidated

Mrs Rose reported a good relationship with one nurse on the ward, whose reassurance she had appeared to find of some help during her delirium. However, the interactions with nursing staff for the main part appear to have left Mrs Rose feeling that her experiences were invalidated. The experience of having a sense of reality different to that of the nurses clearly left her feeling very distressed and unsupported

she kept coming and saying, I'm a nurse, you're in Leeds Infirmary and I says Leeds Infirmary, I'm in Tenerife, I was disgusted with her [laughing].

However, it was not just the interaction with nurses during her delirium which left Mrs Rose feeling uncared for. She reported feeling belittled by staff who treated her as if she were *daft*. Mrs Rose was careful to delineate between when she was delirious (a time when she too considered herself to be daft) and since the delirium has resolved, yet nursing staff still *treat you as if you're an idiot*.

Mrs Rose reported feeling anxious about her ability to care for herself when she went home, but commented that she was *fed up of myself* because of her reduced independence. However, she seemed unsure that she would get the help she needed.

Well I think that they're trying to do their best love but I'm scared that they're going to send me home like this

Mrs Rose did not appear to have had a good experience of hospitalisation, and she commented *I'm worse now than when I came in*. The invalidating experiences with nursing staff left her feeling unsure that she would be receive the help she needed to cope with her hip fracture.

Case 9 – Mr White

Situation

Mr White lived alone, but appeared to have a very supportive social network including family and friends.

The Delirium

Mr White described being *in a different world* at times during his hospitalisation, and experience which he found *awful*. Mr White reported being unsure of his whereabouts for much of the time and talked about being taken to many different places, e.g. to a place his family grew up, amusement arcades and a place where football cards were being sold. He said he often wondered where he would find himself the next morning. He also reported being unable to recognise a relative when she came to visit him. At the time of interview Mr White commented that these things were less noticeable than when he first came into hospital.

Context of Interview

Mr White appeared in low mood during the interview, and scored in the *Mild Depression* range on the GDS. Listening to his experiences appeared to have therapeutic value for Mr White as this was something that did not seem to have happened much during his time in hospital. When talking to me he initially appeared concerned that his comments would get back to those he was talking about (i.e. nursing staff).

Key Theme: Trying to make sense of delirious experiences

Mr White seemed to struggle to understand his experiences reflecting that it was *so mysterious to me*. At times he seemed to find it difficult to distinguish between what was real and what was not, and frequently used tentative language to describe his experiences.

once I went down they seemed to be places where the old footballers cards in the old way they were selling them...nowt to do with hospital, whether they were or not I'm not sure

For many of the things that happened to him, Mr White had to rely on other's accounts of his behaviour to try to make sense of his experiences

from what I can gather from the relation who used to come, my mind seemed to have, my mind seemed to have gone

In trying to understand the reason for his experiences, Mr White reflected on the psychological impact of his fall and the effect it had on his sense of himself as an active person.

Come as a big surprise to me. I've always been an outdoors man -- cricketer, footballer. There were ... nothing in my life so it gave me a big shock. I suppose it would take me a while to get over.

In addition, he observed the behaviour of other patients to help him understand his own experiences. He observed people *not sort of acting as they should be*, and reflected *I think it's their illness*.

Key Theme: Unease about delirious experiences

Mr White seemed uncomfortable about his delirious experiences and the way he had interacted with others while *in a different world*. He seemed critical of himself in this situation, and tried to distance himself from his experience

I thought George White had been so stupid you know I could just imagine it ... this isn't George White

Key Theme: Reflections on mental state

Mr White reflected that reports of his conversation from his visitors indicated that *my mind seemed to have gone*. Mr White appeared critical of himself for being in this state, and chastised himself for *talking absolute rubbish* describing himself as *foolish* and *so stupid*.

Key Theme: Feeling Uncared for

Mr White described being in *a tremendous amount of pain* from his operation, and talked about the slow process of recovery but acknowledged it was becoming easier

It's hard going when you can't walk. Very hard going. But I do believe it's easing a bit

The slow painful process of recovering from his hip fracture appeared to be made worse by the fact that Mr White did not feel supported or cared for by staff. His descriptions of interactions with staff appeared to make him feel invalidated, not being treated as a person in pain.

they ought to be more pleasant you know. ... And of course the early part of my injury, moving me about was a painful experience and I used to tell them, be careful, be careful and they didn't, they seemed to ignore that, it was me that was suffering, in pain, moving me about, very, very painful.

This sense of being unsupported extended to Mr White's social network, and contrasted with his experiences of being very much cared for and supported when he was at home, by both family and friends.

Now up to me going into hospital it was a regular every day he'd come, and bring me a paper Anything you see, and that seems to have disappeared, There's no need for them to suddenly stop coming

While in hospital, Mr White reported trying to make contact with other patients, but was frustrated when initially he was unable to do so – *that was the most annoying, I couldn't get to know them*. Mr White ascribed his problems of communication to the fact that *there's quite a lot of foreigners so I couldn't get through to them*. However, this is contrary to the observations I made while conducting my research – I did not meet anyone who could not speak English fluently. It seems likely, therefore, that Mr White's delirium was contributing to his difficulties communicating.

Mr White reflected that although he had not spoken to anyone about how he was feeling when things seemed *weird*, he would have found it helpful to have talked with someone who would listen to his perspective and help him assess the accuracy of his experiences

probably it might have been a good thing if I could have spoken to somebody that saw my view, told me where I was wrong

Mr White's delirious experiences seemed to have impacted on his sense of feeling uncared for contributing to his difficulty communicating with others. Conversely, the lack of support he described, with no one to listen to his perspective meant that he felt little help in understanding his delirious experiences.

Summary of participants' experiences

The participants in this study had very different experiences of delirium. Their experiences seemed to be of different levels of intensity, ranging from the *vague feelings* of Mr Brown to the *horrible dreams* of Mrs Plum, the *very frightening* experiences of Mrs Rose and the *awful* experience of Mr White. Participants also varied in their concern at their experiences. Although all seemed unsettled by the experience to some extent, there was significant variation of the impact upon individual participants. Mr Brown appeared to have little curiosity about his experiences and Mrs Grey seemed no more concerned about her delirious experiences than about the at times incomprehensible world of her everyday life. Mrs Amber, Mrs Blue, Mrs Green and Mr White seemed to be more uneasy about their experiences, while Mrs Plum and Mrs Rose seemed overwhelmed by their frightening experiences. Mr Black did not want to acknowledge that he had been delirious at all.

Although the experience of delirium appeared to have affected the participants in different ways, there were some issues that emerged for several participants. These will be discussed in the next section.

Group Themes at Initial Interview

Several issues mentioned by individual participants were reflected in other's accounts of their experiences of delirium. These are discussed here. In considering group themes I have focused on issues upon which delirium has had an impact. It is therefore not an exhaustive account. A summary of key concerns for the group can be found in Table 3.

Table 3 – Key Concerns at Initial Interview

Theme	Participant Number									total	
	1	2	3	4	5	6	7	8	9		
Trying to make sense of experience	♦	♦			♦	♦	♦	♦	♦	♦	7
Unease at delirious experience	♦	♦	♦	♦	♦	♦	♦	♦	♦	♦	9
Used strategies to manage unease	♦	♦	♦		♦		♦	♦	♦	♦	7
Reflections on Mental State	♦				♦	♦	♦	♦	♦	♦	6
Concerns about dependence	♦				♦				♦		3
Not cared for in delirium		♦							♦	♦	3

Trying to make sense of experiences.

Virtually all the participants appeared to be trying to make sense of their experiences of delirium, describing them as *strange*, *funny* or *mysterious*. Only Mr Black, who did not appear to want to think that he had been delirious, and Mr Brown, who appeared resigned to whatever happened to him, did not appear to be in the process of making sense of their experiences. In their attempts to understand their experiences, two participants reported trying to check out their experiences with others (Mrs Amber and Mrs Blue). However, neither seemed satisfied with the responses they received. Participants offered a variety of explanations including medical causes, misperceived elements of the environment and the shock of hip fracture. However, for many the explanations offered did not seem entirely adequate and they appeared to be still struggling to comprehend their experiences.

One reason for this difficulty in understanding their experiences appeared to be that the delirious experiences were outside the normal range of participant's everyday experiences, and did not fit easily with a familiar way of thinking about things, or *schema* (c.f. Barkham, Stiles, Hardy & Field, 1996). Two participants did appear to be actively trying to incorporate their experiences into existing schema: Mrs Amber associated her delirious experiences with modern technology, which she also finds *strange*, and Mrs Plum attempted to make sense of her experience in terms of *dreams*. However, neither Mrs Amber nor Mrs Plum appeared to easily be able to fully accommodate their experiences within their existing schema, Mrs Plum noting *I've never had a dream like it*. Other participants appeared to have no schema with which to try to understand their experiences. As Mrs Rose commented *I've never gone through anything like that before*.

Anxiety about delirious experiences

All the participants in the study appeared somewhat uneasy about their delirious experiences, and many did not want me to tell nursing staff about their symptoms. Seven out of the nine older people interviewed seemed uncomfortable discussing their delirious experiences to a greater or lesser extent, and appeared to use strategies to manage this unease, including minimising, laughing to mask unease, trying to distance self from the experience and denial. An overview of the strategies used by individual participants is presented in Table 4. Only Mr Brown and Mrs Grey discussed their experiences without employing any obvious strategies.

One way of understanding these strategies used by participants is to draw on the psychodynamic concepts of anxiety and defence (e.g. Malan, 1979). When a person experiences as a threat to the self, he or she may use defences to decrease their anxiety

(Martin, 2001). It seems likely that the unusual experiences of delirium are experienced as threatening by the participants, and so anxiety-reducing defences are employed⁷.

Table 4 – Strategies to manage anxiety

Participant Number

Strategy	1	2	3	4	5	6	7	8	9
Minimising	♦	♦	♦		♦		♦		
Using laughter	♦		♦		♦		♦	♦	
Explaining away	♦	♦	♦		♦		♦		
Trying to normalise		♦					♦		
Locating in past							♦	♦	
Distancing									♦
Denial		♦	♦						

Reflections on Mental State

Several of the participants reflected on their altered mental state while delirious, and some appeared concerned about what their experiences meant for their mental health. Participants comments ranged from Mr White's self criticism of himself as *foolish* and *stupid*, and Mrs Grey's reflection that *I must be daft*, to Mrs Rose's opinion of herself as *daft, a fool, and barmy* Mrs Amber's comments that she thinks herself *weird* and *queer*.

⁷ The idea of utilising the psychodynamic concepts of anxiety and defence in qualitative analysis is not new. Hollway & Jefferson (1996; 2000) have discussed the notion of the *defended subject* in qualitative research in order to better understand the relationship between the lived experience of participants and how they talk about it.

Participants also appeared concerned about other's opinions of their mental health. Mrs Amber, Mrs Green and Mrs Rose thought that sharing their experiences with others would make them appear *crackers*, *potty* or *balmy*. Mrs Plum commented that her relatives appeared unsure about her while she was delirious *they looked at one another and then decided that I was, I wasn't*.

Mr Black's main concern was about whether people could be held responsible for their behaviour while confused.

Dependence

Mrs Amber, Mrs Green and Mrs Rose all appeared to have some concerns about independence and their delirious experiences appeared to have influenced their thinking about this. However, for each the concerns were very different. Mrs Amber appeared to feel concerned that the medical staff did not find any more problems as she had enough to contend with already. It seems likely that the idea of a problem with her mind implied yet more loss of independence for a woman who *hate[s]being dependent*. For Mrs Green, the suggestion that she was confused appeared to threaten her role as carer for her husband. Mrs Rose, on the other hand accepted that she needed more help, but her invalidating experiences while delirious had left her feeling uncertain she could get the support she needs.

Interactions with nursing staff

While some participants described positive interactions with nursing staff (e.g. Mr Black and Mrs Green), others reported less than helpful interactions with nursing staff while delirious. Mrs Blue described how despite feeling generally well looked after in hospital, she was unable to get a satisfactory response to her questions about what was going on while she was delirious. Mrs Rose talked about feeling well supported by one member of staff, but generally felt her experiences were invalidated by nursing staff. Mr White appeared to feel unsupported during his stay in hospital, and did not feel that he had the help he needed to help him make sense of his experiences.

Concerns of relatives

Although I did not have the opportunity to talk to many relatives of patients, some participants talked about their relatives in relation to the delirium. Mrs Grey and Mr White both knew about some aspects of their delirious experiences from things relatives had told them. Mrs Plum had tried to involve her relatives in her delusion, asking her son in law to find her a lawyer. It appeared that relatives found the experience of delirium difficult to understand. Mrs Plum spoke of the uncertainty of her relatives in knowing how to respond to her.

Follow-up Interviews

Unfortunately, only four of the nine participants agreed to be interviewed three months later. Details of their scores on measures of overall cognitive functioning and depression can be found in Table 2 at the start of this chapter. Reasons for participants' non-participation in follow-up interviews can also be found in Table 2.

I will begin by offering a case-by-case analysis of the main themes for participants at the time of the follow-up interview and note comparisons with their presentation at the first interview. I will then consider key issues raised as a group.

Case-By-Case Analysis

In this section for each of the four participants I will provide an update on their situation, and give details of the context of the interview before considering the key themes which emerged during the second interview.

Mrs Amber

Update on situation

On leaving hospital Mrs Amber had spent some time at a rehabilitation nursing home before moving back to her own house. Although she reported her leg was improving, she still used a trolley to support herself when walking about.

Context of Interview

I interviewed Mrs Amber at her home. She appeared pleased to see me and was happy to reflect on her experiences of hospitalisation.

Key Theme: Finding a new balance between dependence and independence

This theme was still prominent in Mrs Amber's conversation during the follow-up interview. She described her efforts to regain independence and to minimise the amount of help she needed, for example telling the support worker she was no longer needed on the third day of arriving home - *I'd rather struggle and manage rather than be dependent or be just sitting*

waiting for them. However, Mrs Amber still needed help from her daughter and neighbours, and had only been out of her house once, to spend Christmas day with her daughter, because she was still unsteady on her feet. Fear of falling again seemed to have slowed her progress in regaining independence

I'd love to go out for a long walk but I daren't even try getting down the steps on my own. I'm frightened of falling again.

When reflecting on her time in hospital, the frustration at having to depend on others for her care was again evident. She stated that she *wouldn't be happy* about the prospect of going into hospital again because of her dislike of *not being able to have a mind of your own.*

Mrs Amber reflected it may have been helpful to talk about her delirious experiences at the time but noted that *there were never nurses around at that time.*

It might have been better if I'd got someone to talk to or listen to me

Key Theme: Trying to make sense of delirious experiences

Mrs Amber initially reported that she could not recall her delirious experiences *it's gone completely from my memory*, although she noted *I know there was something quite weird.*

When I reminded her of the experiences she had described to me while in hospital, the experience of déjà vu in particular still appeared quite vivid. Although Mrs Amber stated she had not thought about her experiences since leaving hospital, she seemed to be still struggling to make sense of them.

it only just came to mind when I was talking to you. I remembered it and it was so clear, and so strange, I don't think I will ever completely forget those TV programmes that I had seen before. I knew I'd seen them before

Mrs Amber's thinking about possible explanations for this experience did not appear to have moved on from the time we spoke in hospital. She had no ideas about what had caused it and could not see how it could be linked to her physical problems

I think it was very, very strange, very strange, and I mean anaesthetics and broken hips have nothing to do with that, have they?

In looking for an explanation, she considered attributing her experiences to the stress at being in hospital, although she did not appear convinced by this explanation

I think it was actually the hospital, I mean they were driving me around the bend. Sending me doollally as I said. [laughing]

Key Theme: Unease at delirious experiences

Mrs Amber discussed her experiences with me openly and stated that she does not dwell on things that are wrong *once they've been and gone I put them in the past*. However, despite trying to locate her experiences in the past she seemed somewhat unsure whether her experiences may be an ongoing issue

I'm going a bit doollally I think, or maybe I was then. [laughing]

She frequently laughed, especially when commenting on what her experiences may indicate for her mental state and tried to dismiss them stating *I'm just amused really*. However, this seemed in contrast to her next statement that *I can't make head or tail of it. I can't see a reason for it, but I know it was definitely there*.

Key Theme: Concerns about Mental Health

Mrs Amber described herself as *doollally* and explained that this meant *a bit funny in the head*. However, being *funny in the head* is something that she did not want to happen to her, and she said that if it did happen *I'd say shoot me. I couldn't live like that No I'd never want to be like a cabbage, never*.

Mrs Amber stated that she thought her experience was *a one off*, but she seemed concerned that having similar experience in the future might mean something seriously wrong with her mind.

R: *How would you feel if it did happen again?*

Mrs Amber: *I think I'd tell them to send for the men in the white coats to take me away. I don't know, what I would do. I certainly would think about it more seriously than I have done, because if something like that happens, there's obviously something wrong either in the brain or somewhere*

Mr Black

Update on Situation

Mr Black reported that he did not venture outside for around 8 weeks after his operation. However he was now using one stick to get around, and had been driving for a couple of weeks.

Context of Interview

I interviewed Mr Black at his home. He and his wife had gone to some effort to prepare for my visit, laying out a selection of biscuits for me and offering me coffee before the interview. After coffee, Mr Black suggested we move to the dining room table, which gave a more formal situation to the actual interview.

Mr Black appeared to be careful of what he said during the interview with me, and seemed keen to present a positive image of his recovery. Before we began the interview, Mr Black commented that although other residents had remarked that he was making good progress in his recovery, he felt less sure of this. However, once I had started the interview, Mr Black did not talk about this, despite me asking about it. When I asked, he immediately talked about the positive progress he was making, and did not allude to his uncertain feelings about this.

Key Theme: Adjusting to becoming older

During this interview it became clear that Mr Black was in the process of adjusting to a new stage in his life, and he explained that he and his wife had returned from Spain *because the time had come to wind down*. Mr Black again talked at length about the past and his previous capabilities, but acknowledged he was no longer able to do the things he used to, and needed help. This appeared to be a significant loss for him.

We have a man coming to put a shelf in the cupboard there... it wouldn't have been a problem to do that for me but now ...we have to get someone to do it, the first time ever, but, I suppose there comes a time, even if you're fit enough or well enough. ... So that's the thing, missing doing all these things

However, he appeared to be trying to accept his new situation, and frequently contrasted his expectations for his recovery with those for a younger person

I wouldn't expect too much at my age, not like a young person, obviously, they would very quickly get sorted out.

Similarly, in reflecting on his experience of hip fracture, Mr Black commented *it's one of those things that's had to be acceptable because I knew that you can't change what is*

Key Theme: Unease at delirious experiences

Mr Black again appeared uncomfortable with the idea that he had been delirious, and dismissed his experience of being uncertain about his whereabouts immediately after surgery as short-lived and normal when in an unfamiliar environment.

You've only got to go away on holiday for instance, you go into the hotel and on the first night, when you wake up for a split second, you're there but you might be, if you didn't open your eyes you'd probably want to turn the alarm off or something daft like that, you put your arm out but it's not there because you're not at home you're in a hotel. But that's because you're half asleep.

He also appeared keen to emphasise that he had not had any similar experiences since returning home, stressing *No. Oh, no. I know full well where I am*

Mr Black again seemed to want to distance himself as much as possible from the suggestion that he could have been delirious, and stated that *nothing strange* had happened to him while in hospital. He again contrasted himself with other patients whose delirium he had witnessed.

I have seen people while I've been in hospital that have obviously been confused as to where they were. And they try to make it as difficult as they can for the nurses, people falling out of bed and getting out of bed when they shouldn't do and that sort of thing. ... those are the sort of people you're talking about, no nothing like that, I'm quite with it when I'm awake

In talking about people he had witnessed with delirium, Mr Black appeared uncertain about whether they could be held responsible for their actions. He moved between being very critical of their behaviour, reasoning that they must do it on purpose from the way they spoke (e.g. saying they don't need a bedpan then 5 minutes later wetting the bed), and reflecting that perhaps they are not aware of what they are doing and reasoning that the confusion may be a temporary state

and they don't know they're doing it and other times they're probably quite all right.

Awareness of the behaviour appeared to be an important factor to Mr Black in ascribing blame. He spoke of a time recently where medication he was on had side effects that his wife commented afterwards had changed aspects of his personality, but of which he was unaware. However, despite being unaware, he still appeared to feel guilty about his behaviour commenting *you can only say "I'm sorry", but I knew nothing about it. What can you do? You can't do anything really*

At the end of the interview, Mr Black tried to distance himself further from the idea that he could have been delirious, reflecting that delirium is not associated with hips, and then denying he had had hip surgery.

It's not the hip, people go in have a hip replaced and are in and out while I'm still there...But you said from the hip operation. Mine is half way down my upper leg

Key Theme: Attitude to hospitalisation

In reflecting on his time in hospital, the most significant point for Mr Black appeared to be regaining his independence after being so heavily reliant on others

The main thing was when I first go out of bed on a zimmer...the only other thing I remember was not being able to get out or into bed without assistance, and sitting up in bed was quite a job

However, Mr Black commented that he preferred to focus on getting on with things, rather than dwell on his experience of hospital commenting *I never think about the hospital, it's gone. All I'm bothered about is today, tomorrow, that sort of thing.*

Mr Black reported having concerns about the idea of going into hospital in the future. His worries were linked to media reports of the poor level of cleanliness in hospitals and the risk of hospital acquired infections, despite reporting very positive experiences of care during his recent hospitalisation and observing that the wards at the LGI were kept very clean. The idea of being delirious while in hospital appeared to be something Mr Black did not seem comfortable with, which appeared to be linked to his uncertainty about the responsibility of delirious people for their actions.

R: How would you feel if you went into hospital and you got confused in a similar way to the people you've described to me?

Mr Black: Do they always know that they're confused? ... That's the point, are you aware?

Mrs Green

Update on situation

Mrs Green reported that she had only been in hospital for one week before being discharged back home, where community nurses had come to visit and dress her wound.

Context of Interview

I interviewed Mrs Green at her home. She appeared very pleased to see me and to have the opportunity for another social connection as she had been limited in her activities since fracturing her hip. Mr Green was present in the room throughout the second interview, but did not participate and seemed largely oblivious to what was happening around him.

Key Theme: Recovery from hip fracture

Mrs Green described feeling cautious about going out because of her fear of falling again, and reflected *it's just getting my nerves back now to go out.*

However, Mrs Green tried to focus on the positive aspects of her situation, commenting on how her recovery had exceeded her own, and others', expectations

right from first, people couldn't believe I was walking round the house when I come home

Mrs Green seemed pleased that others were looking after her, and happy to allow them to take control in making decisions. *I don't know anything about it, but they've done a damn marvellous job.* Again, she noted the support she felt from medical staff who talked to her *not as if they were nurses* but discussed things with her *so you understand what they're talking about.*

This care and support from health professionals was still available to Mrs Green on her return home, with community nurses coming to look after her, and she reflected *if you've somebody backing you like that, that gives you confidence.*

However, Mrs Green seemed keen to put the experience in the past and get on with her life

Now it's finished with, it's finished with, just get moving and that's it. I never like owt that stops my doing ordinary life

Key Theme: Trying to make sense of delirious experiences

Mrs Green said that she had not thought about her delirious experiences since leaving hospital, and had not had any unusual experiences since coming home stating *As soon as I come home I felt back to normal.*

However, when I reminded her of them the images appeared to be clear in her mind, although she still appeared unsure of the reason for her experiences

I can remember it as though I was looking at it there, I just don't know what made it come like that

Mrs Green reported that she had not been given any explanation for why she might have had unusual experiences while in hospital, but offered many explanations of her own throughout the course of the interview. In fact each time she mentioned an experience she provided an explanation for it, sometimes offering several explanations at once.

but as I say it was the lights and it was probably getting dawn or what have you, getting lighter with that as well but, but I can remember thinking that someone was sat on those seats and probably they had been love or they might have put something on them to make you know moving stuff and that and or a trolley or summat like that

However, she did not appear fully convinced by any of her explanations, and made comments such as *it was really strange and so funny.*

While in hospital Mrs Green had made the temporal association between her anaesthetic and her experiences. However, in the second interview she did not appear to think of this as an explanation. In fact, she commented that having an epidural meant that she had none of the

after effects she would expect from a general anaesthetic, *such as being sort of dopey all the time.*

Mrs Green did, however, link her experiences while in hospital to other ‘unusual’ experiences she has had, commenting that her mother (who has died) *comes anytime that I’m worried, and talks to me...and that gives me strength.*

Key Theme: Unease at delirious experience

As when I first talked to her, Mrs Green still appeared anxious and guarded about her delirious experience. She seemed keen to minimise her experience, offering a range of explanations immediately to dismiss the experience as explicable and not indicative of anything wrong with her

I still think it was all the lights coming through them, you know back lights and then sort of lights moved round you know when it got lighter, it was same, you know but I never even felt poorly while I was in hospital. I never felt anything is not working.

Mrs Green appeared keen to locate her unusual experience in the past. When I asked if she had noticed anything unusual since leaving hospital, she interrupted my question to state that she had not. She did not seem to want to think about the idea of having similar experience in the future, commenting *I don’t think owt like that.*

Key Theme: Concerns about others perceptions of her Mental Health

Again, Mrs Green’s main concern appeared to be that others might think she is *funny*, but later tried to dismiss this stating *I don’t think they’d have bothered.* Mrs Green also appeared concerned about how people would perceive her mental state if she discussed her visions of her mother with them *you daren’t tell them because they thought you were bloody stupid.*

When I asked Mrs Green if she thought she was *funny*, she appeared keen to dismiss this suggestion. She denied it emphatically, and emphasised her capabilities in her role as carer both to her husband and her grandchildren, commenting on her good health for someone of her age *I don’t feel no different to what I did 20 years ago.*

Key Theme: Identity as care-giver

Mrs Green’s role as care giver was again a prominent feature of her discussion in the second interview. Mrs Green talked of her role as carer for her husband, and also for her grandson. She also frequently mentioned incidents where she had looked after others – for example the

woman in the next bed with dementia, or the young woman across from her who had few visitors. This role as care giver in fact appeared to be a significant motivator for Mrs Green in her recovery

I didn't sit on my bum and not do owt you know. I was seeing to him and all that

Mrs Grey

Update on situation

Mrs Grey's daughter reported that she often stayed in bed for much of the morning. Mrs Grey said that she was able to move around the house using two sticks, although she did not go upstairs.

Context of Interview

I met Mrs Grey at her daughter's house. She was still in bed at the time of interview, but was happy to conduct the interview from her bedroom. She again appeared to place me in an expert role, and asked me questions about the details of her admission and whether she was making appropriate progress with her recovery.

Mrs Grey's daughter reported feeling very concerned about her mother when she was repeating the alphabet. She commented that no-one offered an explanation for her mother's odd behaviour, and at the time was worried that it might be a permanent state.

Key Theme: Struggling to make sense of the world around her

As when I first met her, Mrs Grey appeared to have difficulty recalling recent events, although she had a very clear memory for her fall. This made answering questions about her time in hospital a bit difficult to answer, and she frequently talked about things seeming on the verge of her memory. She commented that I had *come a bit too late* and said *if you'd come earlier everything would be fresher*. She did not appear concerned about her difficulties in remembering, stating *I sort of forget things and get on with it*.

Key Theme: Reflections on Hospitalisation

Mrs Grey did not talk much about her hip fracture, and appeared to accept the situation she was in commenting *I can't expect to be running about at my age*.

Mrs Grey used her past experience of being in hospital as a child to help her reflect on her recent experience. However, whereas her childhood experience appeared still very vivid, she struggled to recall her latest hospital admission with the same clarity commenting *that's all fading away now*.

Although she could not recall reciting the alphabet, Mrs Grey did have a vague recollection for the time she thought a film crew had been on the ward noting *Yes, it was something a bit peculiar, what a peculiar sight!*

In contrast to the initial interview, Mrs Grey offered some reflections on why she may have had unusual experiences. She reflected that her experience of seeing a film crew was likely to have been a misperception of something that happened commenting *there must have been something, people or something*.

Mrs Grey again associated her recital of the alphabet with a Christmas party game, but was uncertain of why she did it in hospital. However, she did not appear too concerned to find an explanation for this behaviour

Why, what made me do that I have no idea. Maybe I just did it, you know

The explanations Mrs Grey gave for her experiences were offered tentatively, frequently as questions asking me for confirmation of the details she was attributing as explanations.

Mrs Grey: Had I just had anaesthetic or anything?

R: Yes

Mrs Grey: Oh, that might have been it... Yes, it's probably anaesthetics

While in hospital, Mrs Grey appeared to be unsure about whether she had had unusual experiences or not. When I met her at home, although she still appeared unsure and tentative about her perception that a film crew had been on the ward, she seemed to have a better grasp on her experiences and was able to reflect on them as hospital based phenomena.

It's just sort of natural behaviour in a hospital, isn't it, really?

Mrs Grey reported that she had not experienced anything unusual since leaving hospital, but commented *you don't expect it to happen here*. She did not appear concerned by her experiences, stating *I just took it in my stride really*, and did not expect other people to be more than *mildly interested* if she talked about her experiences with them.

Mrs Grey reflected that she might *expect something similar* if she went into hospital again, noting that in hospital *you expect to feel different*. She did not appear concerned by this prospect.

Group Themes at Follow-up

None of the participants spontaneously recalled the content of their delirious experiences. However, once I had reminded them, Mrs Amber and Mrs Green stated that they could remember the images clearly. Even Mrs Grey had some recollection of the experience of seeing a film crew, though she could not recall repeating the alphabet. Mr Black, however, did not appear to want to recall any experiences that could be classed as delirious. None of the participants reported any delirious experiences since discharge from hospital.

While each of the participants appeared to have thought about their delirious experiences in different ways, it is useful to consider the themes concerning delirium for the group. Table 5 provides a summary of the key issues for participants.

Trying to make sense of delirious experience

Mrs Amber and Mrs Green both appeared to be unsure of the reason for their delirious experiences, reflecting that they were *very strange* and *so funny*. Neither offered a medical explanation on this occasion, in fact they both seemed to dismiss this as a possibility. Mrs Grey, however, seemed satisfied that anaesthetic was the likely explanation for her experiences. Mr Black did not appear to be trying to make sense of his experiences, instead he denied that he had experienced an episode of delirium at all.

Mrs Amber seemed to struggle to fit her experiences into an existing schema, and she commented that she could not see how her delirium could be related to anaesthetics or broken hips. Similarly, while Mrs Green did have some other extraordinary experiences that she likened her delirium to (namely her visions of her mother), the variety of explanations she offered in trying to explain her delirium suggests that she could not comfortably fit her experiences into an existing schema either. However, Mrs Grey did appear to be able to fit her

experiences into her schema of hospitals, commenting that unusual experiences are something she would expect to happen while in hospital.

Anxiety about delirious experiences

The reactions of the four participants to their delirious experiences did not appear to have significantly altered from the time they were interviewed in hospital. Mrs Amber, Mr Black and Mrs Green all still appeared anxious about what their experiences meant for them. Only Mrs Grey seemed unconcerned.

Concerns about Mental Health

Mrs Amber and Mrs Green again expressed concerns about how their mental health may be perceived. Mrs Amber was concerned that she was *doollally* and Mrs Green appeared concerned that others would think she was *funny*. Both seemed keen to leave their experiences in the past, although Mrs Amber did not seem convinced that she could fully do this.

Mrs Grey's daughter commented that as she had been given no explanation for her mother's behaviour at the time, she had been concerned that it may indicate a permanent change in her mother's mental state.

Dependence

Mrs Amber again spoke about her struggle to be as independent as possible. Mrs Green again talked about her role as carer. Mrs Amber's reflections that she does not want to *be like a cabbage* and that if she were *funny in the head* then *the men in white coats* would need to take her away suggests that she perceives having a mental health problem as leading to increased dependence. Similarly, Mrs Green's emphasis on her role as carer in denying any concerns about her own mental health suggests that for her too the experience of delirium may be perceived as a threat to her independence in caring for others, and imply instead that she should be cared for by others.

Mr Black also spoke about his sense of decreasing independence as he adjusted to old age. However, he did not appear to have reflected on how delirium may impact on this.

Reflections on Future Hospitalisations

In thinking about future hospitalisations, Mrs Amber, Mr Black and Mrs Green did not appear to have thought about the possibility of experiencing another episode of delirium, and all seemed uneasy about this idea. Mrs Grey, however, said she might expect something similar to happen again, and did not appear concerned by this.

Table 5 – Key Issues at Follow-up

Participant Number

Theme	Mrs Amber	Mr Black	Mrs Green	Mrs Grey	total
Recall experience after reminder	♦		♦	♦	3
Trying to make sense of experience	♦		♦	♦	3
Unease at experience	♦	♦	♦		3
Reflections on Mental State	♦		♦		2
Concerns about dependence	♦	♦	♦		3
Worried if delirious again	♦	♦	♦		3

Interview Process

During the research, it became apparent that there were important issues concerning the way in which participants (both the older people interviewed and myself) engaged in the research process. These offer further contextual information to the data provided in the case-by-case analyses and are discussed below.

Reaction of Participants to Interview Process

Response to information about study

The information sheets given to patients about the study stated that *many people who break their hips become confused afterwards for a short time* (see Appendix E). Many of the people I approached with information about the research immediately stated that they were not confused. This suggests that the term *confusion* used in the information sheet had negative connotations for those being asked to participate (i.e. older people in hospital following a hip fracture). However, the fact that I wanted to talk to people who had not experienced any confusion allowed people to participate in the research who may not otherwise have done so. For example, Mrs Green initially commented *I'm not confused – it's my husband that's confused*, but agreed to be interviewed about her experiences of hospitalisation.

Reactions to the interview process

All participants were happy to participate in the research, and most seemed pleased to have someone to talk to while in hospital. This is in line with research indicating that boredom and lack of attention are key aspects of older people's experience of hospitalisation (e.g. Koch *et al.*, 1995). I often visited participants after I had interviewed them to say "hello" while I was on the wards recruiting.

Several participants appeared to feel keen to be doing something useful while in hospital by helping me with my research, although some seemed unsure of how much use they could be. Mrs Rose for example, commented

Now whether that's any good to you love, I don't know.

As mentioned earlier in this chapter, many participants appeared cautious about discussing their delirious experiences with me.

Therapeutic benefits of interview process

For some participants the processes of talking to them about their experiences seemed to have therapeutic value. For example, Mrs Rose seemed to want validation for her experiences, asking *Would you have been frightened love?* The benefits of allowing people to discuss their delirious experiences has been commented upon in the literature

It must be acknowledged too, that the very process of interviewing patients about their experiences might be fulfilling a need for therapeutic intervention.

Schofield (1997, pg. 590)

Interviewing Style

Engagement / developing rapport

In interviewing participants, I was flexible about allowing participants to follow their own trains of thought and at times encouraged conversations about subjects other than hips, hospital or delirium. I felt this was important to build a rapport with the individual to enable freer discussion. Discussions about topics not obviously related to the research also enabled me to form a richer picture of the individual and allow me to better understand how delirium may impact on their lives.

Use of language

In talking to people about their experiences, I tried to use non-threatening language to maximise openness. From giving information to people about the study I quickly realised that the word *confusion* appeared to have negative connotations for many people. In the interviews I instead used terms such as *out of the ordinary* or *unusual*. However, it may be that these words also implied negative connotations. Therefore, where possible, I tried to use participants' own language to talk about delirium. For example in Mrs Green's follow-up interview she described her experiences as *like fairy tales*. I asked questions about her delirious experiences using this phrase.

Impact of my own interests

Despite trying to allow the participants the freedom to discuss issues that were important to them, I inevitably was influenced by my own interests in directing the course of the interview. For instance, at times I explored certain areas at the expense of others. For example, Mrs Plum told me that there were people asking her questions but that she thought she mustn't talk to them

R: In your dream, who mustn't talk to you?

Mrs Plum: Well, all sorts of people but I didn't know [laughing] and you know, I don't know what it was but – and they were going to put a tape on television [laughing]...

R: So what was on this tape they were going to put on television?

It might have been useful to persist with the questions about who the people were to see if she was referring to specific people, e.g. medical staff or whether this experience was an hallucination, but I decided to follow the line of the content of her delusion instead.

Interaction between Researcher and Participants

My role as non-medical professional

I introduced myself to participants as a Trainee Clinical Psychologist and explained that the research I was conducting was part of my training at the University. Participants appeared to view me as a student, and frequently seemed to put me in a 'granddaughter' role. It is possible that people spoke to me differently than they would a qualified health professional. The fact that several people discussed their experiences with me, but did not want me to inform medical staff suggests that I was not viewed in the same way as other health professionals. It may be that as a student I had no power to make decisions about care and so telling me about their symptoms did not have the potential consequences, such as increased hospital stay, that telling medical staff may have.

Impact of delirium

At times symptoms of delirium impacted upon the interaction during the interview. Mrs Blue appeared distractible throughout the interview and made it difficult to gather information about her experiences from her. This distractibility is likely to have been a symptom of her delirium, and it seems likely that symptoms such as this impair communication between patients and nursing staff.

Dynamic reinforcing dismissal of experiences

As discussed earlier in this chapter, participants adopted many strategies to manage their anxiety around the experience of delirium. I was aware of this during the interview process, and often felt I was being encouraged to reinforce the individual's dismissal of their experiences, rather than helping the individual to explore their experiences in a way that helped them to understand and feel comfortable with them. For example:

Mrs Amber: I haven't been taking things in and I'm not seeing as well as I ought to and that screen is so small, no one likes it you know, it's very small is that screen for a big room like this

R: It's tiny isn't it

It is possible that this caution about discussing delirious experiences is a result of an idiosyncratic dynamic between the participants and myself. However, other researchers have also commented that patients with delirium may try to mask their symptoms (e.g. Mackenzie & Popkin, 1980) so it seems likely that this dynamic is one that other people may experience.

My Expectations

Although reluctance to discuss delirious experiences is mentioned in the literature, it is referred to in a minimal way and I did not expect people to appear so cautious in talking about their delirious experiences with me. In fact, I initially felt frustrated with Mrs Blue for her reticence at talking about her experiences of confusion as she had already commented to me that she thought she had been confused. However, I soon realised that this caution was a significant issue for this group of patients. Similarly, in the early stages of the research I was often surprised when participants revealed symptoms of delirium in the middle of the interview. In later interviews people seemed much more open about discussing their experiences with me. These people described more intense experiences than those interviewed initially, and nursing staff were more aware of their delirium. However, it may also be that my interviewing style developed to become more sensitive to participants' anxieties.

Chapter Summary

In this chapter I have given details of the participants and presented the results of the case-by-case analyses for the first and follow-up interviews, offering reflections on key issues for the group on both occasions. In addition, I have reflected on the interview process to offer an enriched understanding of the process of the research. In the next chapter I will offer a focused discussion of these findings.

DISCUSSION

In this chapter I will begin reviewing the main findings of the research in the context of the existing literature. I will then offer reflections on the research process. The limitations of this study will be considered, and possible improvements suggested. Finally, I will consider future directions in the field of delirium, both in terms of research and in possible improvements to clinical practice.

Discussion of Main Findings

The aims of this study were to explore how older people who become delirious after reparative hip fracture surgery make sense of their experiences, both during their time in hospital and three months later. In addition, perceived potential implications for future hospitalisation were considered.

Perhaps unsurprisingly, at the time of the first interview, most participants seemed to be struggling to make sense of their delirious experiences, and many did not appear convinced by the explanations they suggested. Attempts to understand the experience of delirium have been observed in other studies of older people's experiences of delirium after orthopaedic surgery (Anderson *et al*, 1993; Andersson *et al*, 2002b) and studies of delirium in other populations (Laitinen, 1996; Fagerberg & Jönhagen, 2002; McCurren & Cronin, 2003). However, Schofield (1997) reported that participants in her study showed little interest in looking for explanations for their experiences of delirium. Instead, she commented that they seemed to be trying to forget the whole thing.

All the older people in this study appeared uneasy about their delirious experiences. This unease may be due, at least in part, to difficulties assimilating their experiences into a pre-existing schema. The assimilation model (cf. Barkham *et al.*, 1996) suggests that while people try to assimilate their experiences into pre-existing schemas, a *problematic experience* can cause psychological discomfort such as anxiety, fear or sadness as it cannot easily be assimilated into an individual's schema. The idea of problematic assimilation of experiences has been used by several researchers to understand posttraumatic stress disorder (PTSD). Horowitz (1986) suggested that one response of people to a traumatic experience is to try to assimilate the trauma information with existing beliefs about the world. He suggested that the difficulty in matching the thoughts of the trauma with existing beliefs creates a tension which psychological defence mechanisms such as denial and avoidance are used to manage.

However, the fundamental need to assimilate the new trauma information with old beliefs causes the trauma memories to break into consciousness as intrusions, flashbacks or nightmares. Similarly, Janoff-Bulman's (1992) *Theory of shattered assumptions* (described in Brewin & Holmes, 2003) suggests that PTSD symptoms occur when key assumptions about the world (e.g. that the world is meaningful) are shattered by a traumatic event. More recently, Ehlers and Clark's (2000) cognitive model of PTSD (described in Brewin & Holmes, 2003) suggests that the memory of a traumatic event is not given a complete context in time and place and is not properly integrated with existing autobiographical knowledge. The key role of assimilation in theories of PTSD and the difficulties described by participants in this study in assimilating their delirious experiences with pre-existing schemas may suggest that they are at risk for developing PTSD symptoms. However, none of the participants interviewed at follow-up appeared to have intrusive thoughts or flashbacks relating to their delirium. The small number of participants who agreed to be interviewed after three months may not be fully representative of this group, however. While still in hospital, Mrs Rose stated several times that she wanted to forget her experiences, but was unable to do so and became frightened when she thought about them. She declined to be interviewed at follow-up. Similarly, Mrs Plum, whose experience of hospitalisation appeared to be dominated by her *horrible dreams*, stated that she did not want to participate in the follow-up interview because her experience of being in hospital had been very stressful and she did not want to talk about it again. It may be that for these participants there was some element of PTSD symptoms, but the lack of follow-up interviews makes it impossible to know for sure.

The majority of participants in this study appeared uncomfortable talking about their delirious experiences. While this has been noted in a handful of participants in other experiential studies of delirium, it has not been greatly discussed (Andersson *et al.*, 2002b; Schofield, 1997). Methodological differences may partially explain the small number of participants in the study by Andersson and colleagues who appeared uneasy about talking about their experiences (five of the fifty-one participants did not want to discuss experiences at all, and three seemed not to remember until they were given details of their behaviour while delirious). The fact that participants were given information about the possibility of developing delirium prior to their episode of confusion may have lessened their unease about it (c.f. Owens & Hutelmyer, 1981, who reported pre-operative education about delirium significantly reduced cardiac patients' unease at subsequent delirious experiences). In addition, Andersson spent a large amount of time with participants during their delirium, observing and making notes on their experiences. Therefore a comfortable relationship may have been established with participants prior to interview, which may have lessened unease about discussing experiences.

The unease in talking about delirious experiences is a very important issue when considering delirium. The defensive strategies used by the participants in this study to manage their anxiety frequently created an interaction which seemed to encourage the experience to be dismissed without much discussion. This seemed to be a powerful dynamic, but by having exploration of delirium as the focus of my conversation, and by becoming increasingly aware of the processes in the interaction, I was able to move beyond it and explore in more detail participants' experiences. It seems likely that similar processes occur when health care professionals talk to patients about delirium, and in fact some authors have suggested that patients may try to hide their symptoms, or disguise attempts to get information about their experiences when interacting with nursing staff (Mackenzie & Popkin, 1980; McCurren & Cronin, 2003). However, typically nurses' interactions with patients are not explicitly aimed at detecting delirious symptoms, and they are likely to be unaware of the strategies that patients may use to manage their anxiety. This could in part explain the poor detection of delirium by health care staff, and is also likely to lead to patients not getting the support they need to make sense of their experiences.

Nearly half of the participants reported feeling inadequately supported by nursing staff both during, and after their delirious experiences, although this was not an issue for everyone. This lack of support has been reported in other studies of older people's experiences of hospitalisation (Koch *et al.*, 1995). However, in the current study for some participants delirium appeared to have had a direct impact on the level of care and support some patients felt they needed in contrast to the care they felt they received.

Many authors have noted that nurses do not feel comfortable in managing patients with mental health problems such as delirium (Atkin, Martin & Holmes; *in press*; Brinn, 2000; Castledene 2004; Goodwin, 2001; Hallberg, 1999). General nurses have reported feeling unskilled in recognising and managing mental health conditions (Atkin *et al.*, *in press*) and may feel uneasy about the abstract nature of working with the thoughts and feelings of a patient (Castledene, 2004). In addition, nurses may find it difficult to communicate with a patient whose actions appear meaningless (Hallberg, 1999), or whose sense of reality seems different than those of nursing staff (Andersson *et al.*, 1993; Andersson, Hallberg & Edberg, 2003). The anxiety created by working with these patients is likely to activate unconscious defences within the nursing staff and influence their behaviour towards patients with mental health problems, such as withdrawing from them or limiting their interactions with them (Goodwin, 2001). The defensive strategies of nursing staff are likely to interact with the defensive strategies of the patients, further exacerbating the difficulties of detection and discussion of delirious symptoms.

The symptoms of delirium include hallucinations, illusions, misperceptions and cognitive impairment, so it is hardly surprising that many participants in this study were concerned about their mental state and mental health. There are some notable similarities between the experiences of people with delirium and those of people with other mental illnesses, such as schizophrenia, for example, the sense of being overwhelmed by the psychotic experiences and the inability to interact with the world in a usual way (Hirschfield, Smith, Trower & Griffin, 2005). The fear of stigmatisation has been described by several authors discussing the experience of mental illnesses such as psychosis and schizophrenia (Chadwick, 1997; Haywood & Bright, 1997; Knight, Wykes & Haywood, 2003). Concern about how others may judge their mental health was clearly an issue for many participants in the current study, and it seems likely that the stigma associated with mental health problems may explain some of the anxiety they expressed. However, despite their similarities, the experience of delirium is markedly different from other mental illnesses with similar symptoms. Delirium is an acute syndrome, where symptoms develop over the course of hours or days. In contrast, in other psychotic illnesses such as schizophrenia or schizoaffective disorders symptoms are present for at least one month, and frequently last longer (American Psychiatric Association, 1994)¹. The duration of symptoms in these conditions is likely to affect the way in which people make sense of their experiences, limiting the comparability with people who experience mental disturbance lasting only a few days, as in delirium. Delirium can be further distinguished from other similar mental illnesses by its fluctuating nature whereby a person's mental state can vary between lucidity and confusion during the course of the day. This difference is also likely to have an impact on the lived experience of the symptoms, reducing comparability with the experiences of people who have other kinds of psychotic illnesses.

One fear of many older people is that they will develop dementia (Corner & Bond, 2004), and it may be that participants in this study had similar fears, particularly given their experience of an episode of cognitive disturbance. Several participants referred to themselves as daft, stupid or foolish. This sense of feeling intellectually substandard has been noted in people who have dementia (Preston, Bucks & Marshall, 2005; Reed, 2002), and participants in these studies have used similar words to describe themselves, e.g. silly or stupid. However, the short duration of delirium makes the experience different from that of people with dementia. Reed (2002) noted that several participants in her study of the experience of delirium expressed negative reactions to their symptoms of dementia, reflecting that it is *Horrible, Horrible...Just*

¹ The exception to this is Brief Psychotic Disorder, which lasts more than one day but remits within one month. I have not found any literature on the experience of Brief Psychotic Disorder with which to compare the experiences of participants in this study.

knowing that it's going to stay like that (pg. 32). None of the participants that I interviewed directly expressed concerns that their delirious symptoms would be permanent. However, there was an indication that other people were not able to make this distinction. Mrs Grey's daughter reported initially feeling concerned that her mother's delirious symptoms would be permanent. Similarly, Mrs Rose commented on the way she was treated by nursing staff as if she was *daft* after her delirium had resolved. Other researchers have noted that older people in hospital report being treated by nursing staff as having declining cognitive abilities (Koch *et al.*, 1995). It is likely that the presence of delirium may lead nurses to assume an ongoing cognitive impairment, rather than recognising it as an acute condition. McCarthy (2003) has observed that this may be in part due to nurses' preconceptions about ageing.

Although it is clear that for many participants concern about their mental state was a significant issue, it was not possible in this study to accurately distinguish concerns about dementia from concerns about mental illness more generally. While these concerns have not been explicitly reported in older people who have experienced an episode of delirium following hip fracture, they have been suggested by other authors. Fawdry & Berry (1989) described two anecdotal case studies of older people with delirium, and commented that both felt as if they were losing their minds while delirious. The authors associated this with a fear of senility, although it is unclear why fear of senility and not other mental illness was the assumed concern of these patients. Similarly, Schofield (1997) noted that two participants in her study of older people's experiences of delirium expressed concerns that they were going mad. However, she comments that neither appeared to explicitly link this with dementia or senility.

Despite not being explicitly reported in elderly hip fracture patients, these issues are likely to have been present for participants in previous studies (Andersson *et al.*, 2002a). Although the authors do not refer to participants' reflections on their mental health, quotes included in the paper to illustrate other themes suggest that this was an issue for some participants: *They were crazy things. I was not really all there and I am old too so it is not so strange if I am a bit gaga* (pg.659).

The experience of hip fracture has been associated with significant psychological consequences (Borkan, Quirk & Sullivan, 1991). Concerns about increased dependency (Archibald, 2003; Borkan *et al.*, 1991; Furstenberg, 1986; Robinson, 1999), social isolation (Borkan *et al.*, 1991) and fear of falling (Archibald, 2003; Borkan *et al.*, 1991; Mckee, Orbell, Austin, Bettridge, Liddle, Morgan & Radley, 2002) have been observed in older people following a hip fracture. In their study of 80 hip fracture patients over the age of 65, Borkan *et*

al (1991) reported that feeling more dependent and alienation from social group appeared to be associated with slower ambulatory improvement 3 and 6 months after the fracture.

Delirium has been found to have a negative impact on independence after hip fracture (Holmes & House, 2000b) and decreased independence appeared to be an issue for several participants. However, the precise concerns of the individuals were different, and their delirious experience seemed to have impacted on this issue in different ways. Some appeared to view their delirium as a potential threat to independence, another felt unsure of support in her increasingly dependent state, and another acknowledged his decreasing independence, but had not considered the impact of delirium upon this. The variety of responses to the issue of dependence serves as an important reminder that while some generalisations can be made, it is essential to recognise the idiosyncratic concerns of the individual patient.

While concern about social isolation was not a theme for the majority of participants in this study, one man seemed to be troubled by his sense of social alienation which appeared to be exacerbated by his delirium (he did in fact have frequent visitors). Unfortunately he did not complete a follow-up interview so it was not possible to explore whether this sense of isolation while delirious had any longer-term implications. As none of those who were interviewed at follow-up described feeling alienated from their social supports it was not possible to examine the impact that an episode of delirium may have had upon this.

Fear of falling was not an issue described by any participants at the time of the initial interview. However, at follow-up two participants described their caution about walking and fear of falling again, although it was not clear whether or how their experience of delirium may have impacted upon this.

Longer-term implications

Three months after the first interview, most of the participants still appeared uneasy about their experiences, and uncertain of how to make sense of them. Only one participant seemed comfortable locating her experience in hospital and happy with her explanation that it was due to the anaesthetic. This is in line with Fagerberg & Jönhagen's (2002) observation that participants who were interviewed up to a year after their experience of delirium appeared to be struggling to make sense of their experience. The concerns articulated by the participants did not appear to have substantially changed from the time I interviewed them in hospital.

Research indicates older people use past experiences of hospitalisation to make sense of current experiences (Koch, *et al.*, 1995). However, none of participants appeared to have

considered how their recent hospitalisation could influence future experiences of hospitalisation. However, this may be a difficult issue to consider prospectively. Unlike participants in Fagerberg & Jönhagen's (2002) study, none of participants in the current research spontaneously stated they were concerned that the delirium may reoccur. However, when asked about the prospect of becoming delirious again, all but one appeared uneasy at the idea.

Dementia and delirium

Studies describing the lived experience of delirium have all either explicitly excluded patients with dementia, or failed to mention whether patients with dementia were included and what their experiences were as a group. However, one participant in this study appeared to be in the early stages of dementia. It is significant that she was able to recall some experiences of delirium, even after three months.

Reflections on the Research Process

The methods used in this study enabled me to get a sense of the lived experience of delirium, and the ways in which participants attempted to make sense of their experiences. In particular, reserving judgement about whether an individual had been delirious until after the interview allowed a rapport to be established that encouraged an openness in responses which may have been missed had I asked questions from the *Delirium Rating Scale* on first meeting people. In doing this, I was also able to include people who had not been observed to be delirious by medical staff. This group of people, who present with more *hypoactive* symptoms of delirium, have been typically missed in qualitative studies of delirium on general medical and surgical wards, as most studies have included participants on the basis of diagnosis by healthcare professionals (Andersson *et al.*, 2002a; 2002b; McCurren & Cronin, 2003; Fagerberg & Jönhagen, 2002; Schofield, 1997). It is only the single case studies that have not explicitly relied on nursing or medical identification of delirium for inclusion in the study (Andersson *et al.*, 1993; Crammer, 2002; Mackenzie & Popkin, 1980).

In analysing the data from the interviews, I used psychodynamic ideas to inform my thinking and reflections, noting the dynamics I had experienced during the interviews, and utilising the concepts of anxiety and defence. In doing this, certain aspects of the data may have been prioritised over others. Researchers utilising other models may have prioritised other elements of the data in their analysis.

In conducting the research, I was mindful of the standards set in the guidelines by Elliott *et al.* (1999) and Stiles (1993). The issues of *owning one's perspective*, *engagement with the material* and *providing credibility checks* were discussed in the methods section. In the results section I gave details of participants and their circumstances to assist the reader in judging the range of people and situations to which the findings may be relevant. By offering illustrative quotes in the case-by-case analyses I hope I have allowed the reader to judge the fit between the data and my interpretations. Through the initial presentation of data for individual cases before reflecting on group themes I hope I have achieved *coherence*. Throughout the research I offered reflections on my own internal processes, most significantly in the *Interview Process* section of the results. However, I acknowledge Stiles' (1993) caution that I may be unaware of some aspects of my internal processes, or may have unintentionally overlooked or distorted them. Finally, I feel that the findings have considerable face validity, and have offered some new reflections on the issue of delirium, but ultimately it is up to the reader to judge whether the research meets the final criterion of *resonating with the reader*.

Limitations and Improvements

There are several limitations to the current research. These will be discussed here and possible improvements to the study suggested.

Issues of consent

A limitation to the current study before it even began was that acting on the advice of the Data Protection Officer I was only able to include participants who were able to give informed consent to participate in the study at the time of interview. It was not possible to gain consent retrospectively, nor to include patients with co-morbid delirium and dementia who were unable to give informed consent. The issue of informed consent in research in delirium is one that has been discussed by other authors. Fick *et al.*, (2002) state that practice guidelines need to be established for consent and studies of older people with cognitive impairment. Similarly, Adamis, Martin, Treloar & Macdonald (2005) reflect on the potential selection bias and therefore limitations to generalisations that can be drawn if participants in studies of delirium must fulfil the criterion of formal capacity to consent. They suggest that assessment of capacity to consent to research should be contingent upon potential harm done to the participant by inclusion in the study balanced against the potential harm of non-generalisable, biased studies. As Adamis *et al.* (2005) observe

If subjects whose mental state is both the subject of inquiry and the reason for lack of capacity are excluded from the study, then knowledge cannot advance satisfactorily. (pg. 138)

In fact, forthcoming legislation allows for the inclusion of patients in research who lack the capacity to consent. It states that patients who lack the capacity to consent can be included in research into the cause or treatment of their impairing condition, where the risk to the patient is likely to be negligible, providing there are reasonable grounds for believing that research of comparable effectiveness cannot be confined to people who have the capacity to consent to taking part in it (Department of Constitutional Affairs, 2005). Qualitative research into the lived experience of delirium would fall into this category, including patients with co-morbid delirium and dementia.

Limitations of sample

The small number of participants in this study limits the generalisability of the results. While saturation of themes is not an explicit criterion when conducting research using IPA, it is possible that more themes would have been identified if a larger sample had been recruited. Therefore it needs to be recognised that themes not captured by this research may be important for other older people who experience an episode of delirium following surgery for a fractured hip. The limitations of generalisability are particularly evident for the themes that emerged during the follow-up interviews, which only four participants completed. It is likely that other themes may be important for older people who have experienced delirium which were not identified by this small sample. It is especially significant that none of the participants who reported particularly frightening experiences while delirious were interviewed at follow-up. These people may have significant concerns not identified during this research.

In giving background information about participants there are some details which it may have been important to include which were omitted in this study. One potentially significant issue may have been to explicitly ask participants about other illnesses or health problems (although some were mentioned by participants). It may be that health conditions other than the hip fracture influenced the way that participants reflected on their delirious episode. Similarly, details of the ethnicity of participants were not specifically obtained. However, all participants appeared to be of White British origin. This again limits the generalisability of the findings, especially because of the cultural variations in understanding mental health and phenomena such as hallucinations (Raguram, Ragu, Vounastou & Weiss, 2004).

In addition, it would have been useful to analyse the data from the interviews with non-delirious hip fracture patients as this may have broadened my understanding of the potential impact of delirium on patients in hospital following hip fracture.

Materials and research process

As a novice researcher my research skills have developed throughout the process of this research. Consequently, there are limitations to this project both in terms of the development of the materials and in the research process.

The practice of creating and using the first interview schedule enabled me to bring more thought to the development of the schedule for the follow-up interview. For example I was more aware of the wording of questions and prompts and more mindful of possibly leading questions (e.g. *please tell me about...* encourages more information than *can you tell me about...* which can be answered with a *yes* or *no* reply). However, in practice the schedules were used as topic guides rather than rigidly adhered to, which probably limited the impact of this.

In retrospect, there are some questions that it may have been useful to include. Some participants appeared to be overwhelmed by their delirious experience at the time of interview, and it was hard to clearly determine their concerns about the impact the delirium may have in the wider context of their lives. It may have been helpful to include a question about the perceived challenges on discharge from hospital in the first interview. This may have allowed greater understanding of their concerns about the implications of recovering from a hip fracture, and enabled an examination of the way in which the delirium impacted upon these concerns.

In addition, neither interview schedules included questions specifically asking about concerns about mental health. In some respects this could be considered a strength of the findings – concerns about mental health were introduced by the participants and not pre-empted by the researcher (c.f. Smith, 1996). However, by not asking about mental illness or dementia it was not possible to distinguish between concerns on both issues. It may be helpful to understand if older people are concerned about dementia or mental illness more generally as this may indicate the information that these people need to help them make sense of their delirious experiences.

My competence at using the screening measures improved with practice. For example, I mis-scored Mrs Blue's *Delirium Rating Scale* initially, which meant that she was not offered a

follow-up interview. My interview technique improved during the research as I became more adept at finding the balance between allowing the participant to talk about the things important to them and eliciting the information I was interested in. Similarly, my analytic skills developed with increasing familiarity with the IPA procedure.

By interviewing people about their experiences I encouraged them to reflect on the delirium. This may itself have had therapeutic value (Schofield, 1997). Therefore, it is important to consider that this may have affected the follow-up interviews and enabled people to be better adjusted to their episode of delirium. However, the opposite may also be true. Talking to people about their experiences while in hospital may have made the experiences more salient and caused participants to think about them more.

One quality criterion not addressed in this research is that of *testimonial validity* - checking out interpretations with the participants (Stiles, 1993). However, this may not have been appropriate in this study as the unconscious defences against anxiety may not be readily acknowledged by at least some participants.

Future Directions

In this section I will discuss future directions that could be explored, considering possible avenues of research and potential clinical implications of this study.

Suggestions for future research

This study has highlighted some important areas in older people's experiences of delirium after hip fracture. However, there is much research still to be done in the field of delirium.

It would be useful to conduct similar research with a larger sample. In particular, a larger study of the impact of delirium in elderly hip-fracture patients after discharge from hospital may uncover more important issues for this population than the current study was able to identify. The possibility of PTSD symptoms following delirium could be better explored in a larger sample. Future studies could also include participants who have experienced delirious symptoms after they have been discharged from hospital as this may influence the way in which delirious experiences are reflected upon.

The experience of hip fracture can have important psychological consequences for older people, such as increased sense of dependence, increased social isolation and an increased

sense of vulnerability, especially fear of falling. While the current study was able to offer some insights into the impact an episode of delirium may have on issues of dependency, the small sample size means this area was not exhaustively explored. Issues concerning the impact of delirium on a person's sense of social isolation and sense of vulnerability were not considered. A study that compares the experiences of delirious and non-delirious elderly hip fracture patients may offer further insights into the psychological impact of delirium following hip fracture.

As previously noted, it may be helpful in future research to try to unpick the concerns about mental health of older people to determine whether their anxiety is about dementia, mental illness more generally, or both. This may indicate the type of information required to help them make sense of their delirious experiences.

The lived experience of delirium in dementia has not been explored other than in the single case in this study. Given the prevalence of delirium superimposed on dementia, and the negative consequences associated with this (Fick *et al*, 2002) it seems important to do further research into this group of patients to increase our understanding of their experiences and needs to enable the best package of care to be delivered. Other qualitative studies of people with dementia have illustrated that people with dementia are able to engage in the research process and offer a rich account of their experiences (Preston *et al.*, 2005; Reed, 2002), and the forthcoming legislation (Department of Constitutional Affairs, 2005) should make it easier to include participants in such studies ethically.

It would be useful to consider the impact of an episode of delirium after hip fracture in older people from different cultural backgrounds to determine if different populations have different needs to help them manage their experiences.

The implications of an episode of delirium may be different for different patient groups. The current study has indicated that hip fracture patients may have specific concerns about increased dependency, and an episode of delirium appeared to impact on this for some people. Research into other patient groups (e.g. cardiac, renal, or cancer patients) may highlight condition-specific concerns which an episode of delirium may impact upon. Similarly, while delirium is particularly prevalent in older people, it can affect all ages. It would be interesting to explore the experience of delirium in other age groups to better understand and care for these patients.

Relatives are frequently witnesses to an episode of delirium, and in the current study one participant's daughter expressed her concerns about her mother's mental state during her delirium. However, to date the research into the experience of relatives is limited to quantitative studies of the families of patients with cancer (Breitbart *et al.*, 2002; Morita, Hirai, Sakaguchi, Tsuneto, & Shima, 2004). The use of qualitative methods to explore the reactions of relatives to an episode of delirium would be a useful contribution to the literature. Relatives' concerns may vary for different conditions, so it will be important to explore their perspective in specific areas including hip fracture, cardiac and cancer.

Clinical Implications

The National Service Framework for Older People (Department of Health, 2001) has stressed the importance of improving the prevention, care and treatment of mental health problems in older people, and has noted that this depends on the early recognition and management of mental health problems. The current study offers some useful clinical insights in line with these recommendations.

Patients with delirium struggle to make sense of their experiences. Therefore, health care staff should facilitate open discussion of their symptoms. An increased awareness of the likely concerns of these patients, e.g. in relation to concerns about mental health or issues of dependency, may help nurses address potentially significant concerns for this patient group. However, nurses also need to be mindful of the idiosyncratic concerns of patients, and be open to discussing the issues raised by individual patients. Talking to patients about their concerns while in hospital may alleviate their concerns both while in hospital and after discharge.

Allowing patients the opportunity to discuss their experiences once the delirium has resolved has been recommended by other authors (e.g. Andersson *et al.* 2002a Mackenzie & Popkin, 1980; Schofield, 1997). In addition, Hallberg (1999) noted that the opportunity to debrief after an episode of delirium may also have therapeutic value for the staff who were involved in caring for the patient while delirious. Despite this, open discussion of delirious symptoms does not routinely occur on orthopaedic wards. One likely contributor to this is the anxiety management strategies employed by patients who have experienced an episode of delirium, which discourage discussion of symptoms. The lack of discussion of symptoms of delirium also has significant clinical implications for the physical health of the patients. Failure to detect delirium prevents the treatment of the underlying cause of the delirium, which is likely to contribute to the negative outcomes associated with delirium (Holmes & House, 2002b). Recognition of the different strategies used should help alert medical and nursing staff to the possibility of delirious symptoms that are being masked by the patient. However, this is not an

easy task, and the powerful dynamic created by the defensive anxiety management strategies may be difficult to detect for clinicians inexperienced in identifying interpersonal processes. This difficulty is likely to be exacerbated by the anxiety of nursing staff when dealing with patients with mental health problems. This anxiety, around issues such as the lack of knowledge about managing with patients with mental health problems (Atkins *et al.* in press), and the abstract nature of working with patients' feelings (Castledene, 2004) is likely to be another factor which hinders the open discussion of delirious symptoms. Therefore, it seems important to offer nursing and medical staff more training and support in working with patients with mental health problems. One way of doing this may be to provide ward-based teaching programmes to help staff develop skills in recognising the ways in which patients may minimise their symptoms of delirium. In addition, offering supervision to nursing and medical staff could help them better understand and manage their own anxieties about working with patients with delirium, as well as facilitate recognition of the anxieties of patients who have experienced an episode of delirium. The Royal College of Psychiatrists (2005) has stated that education and training in general hospital is a key role for mental health liaison services.

Alerting patients and relatives to the possibility of delirium prior to surgery may help alleviate subsequent concerns about the delirious state. Owens & Hutelmyer (1981) reported that giving cardiac patients information about delirium prior to surgery significantly decreased feelings of discomfort when confronted with a delirious experience. The same should be done for patients undergoing surgery for hip fracture, and delirium specifically stated as a possible consequence of surgery. In addition, information about delirium should also be readily available for both patients and relatives on return from theatre. This could be accomplished by producing a leaflet covering the common symptoms of delirium, which could be given to all hip fracture patients and their families.

Concluding Comments

Despite its small size, this study has, I hope, offered some useful insights into the experiences of older people who become delirious after surgery for a fractured hip. While there is much research still to be done in the field of delirium, useful suggestions for improvements to clinical practice have been offered.

The process of conducting this research has given me an added bonus. Through learning about others experiences of delirium, I have come to better understand my own delirious experiences.

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Appendix A

Literature Search Strategies

Two data bases, MEDLINE (1966 onwards) and PSYCH-INFO (1896 onwards) were searched for relevant papers using the following strategies:

\$ indicates a truncation, e.g. confus\$ searches for all words with this root (e.g. *confused, confusion, confusional*).

adj 5 indicates that the two words specified should occur within 5 words of each other (e.g., acute adj 5 confus\$ should identify papers including *acute confusion* and *acute onset of confusion* etc.)

Experience of delirium

delir\$ OR acute adj 5 confus\$ OR ICU psych\$

AND

qual adj 5 research\$ OR interpretative phenomenological analysis OR grounded theory OR discourse analy\$ OR experien\$ OR phenomenolog\$

Limit results to English Language

Older people's experience of hospitalisation

hospitali\$

AND

qual adj 5 research\$ OR interpretative phenomenological analysis OR grounded theory OR discourse analy\$ OR experien\$ OR phenomenolog\$

Limit results to English Language and to age 65 years and over

Experience of hip fracture

hip adj 5 fract\$ OR femur adj 5 fract\$ OR femor adj 5 fract\$

AND

qual adj 5 research\$ OR interpretative phenomenological analysis OR grounded theory OR discourse analy\$ OR experien\$ OR phenomenolog\$

Limit results to English Language and to age 65 years and over

Abstracts identified by these searches were reviewed for relevance and papers obtained.

References of significant papers were also examined to identify additional papers not captured by the search strategies.

Appendix C 1

Interview Schedule 1

I'd like to spend some time talking to you about your experiences of being in hospital...
Maybe we could start with you telling me about what brought you into hospital...

1. What has it been like for you being in hospital?
Prompt: How are things different than normal?
Prompt: Is anything different from what you expected about being in hospital?

- 2.1 Some people notice strange things going on after a hip operation – have you noticed anything strange or out of the ordinary? Can you describe your experiences?
Prompt: Have you seen people / things that you didn't expect to see here? (E.g. people from your past that you haven't seen for a long time)?
Prompt: Have you seen things going on that you didn't expect to be going on? Anything odd that you wouldn't expect to be happening in a hospital?
Prompt: Do you ever wonder where you are since your operation?
Prompt: Do you ever feel that that someone might try to harm you while you have been in hospital?
Prompt: Have you noticed any very vivid dreams, or feelings that you are dreaming while you are awake since your operation?
Prompt: Have you had any odd sensations while you have been in hospital – e.g. feeling unreal / feeling that your senses are wide open?
Prompt: Have you done things since you have been in hospital that you feel are out of character for you?

If answered "yes" to question 2.1, continue with questions 2.2-2.6.

If answered "no", move straight to question 3.

- 2.2 When you notice these things, how does that make you feel?
Prompts:
 - Scared or frightened – what is scary/ frightening about them?
 - Happy / entertained
 - Confused
 - Upset
 - angry
 - threatened

- 2.3 Have you talked to anyone else about the odd things you have noticed?
- 2.4.1 *If yes*, how did they react?
- 2.4.2 *If no*, why not? How do you think they might react?

- 2.5 Why do you think that you notice these things happening?

3. Are there things which you find difficult about being in hospital? Can you tell me about these?
Prompt: staff interventions (invasive procedures/ interactions)
Prompt: Other patients

4. Are there things which you have found make being in hospital easier?
Prompt: Interactions with staff
Prompt: People telling you what is going on / where you are etc.
(reorientation)
Prompt: Relatives visiting
Prompt: Other patients
Prompt: Medication
5. What feelings do you have about being in hospital?
Prompt: Some people find being in hospital scary, other people find it upsetting; other people say they enjoy talking to nurses etc. How has it been for you?
6. Is there anything else about your time in hospital that we haven't talked about today?

Thank you for your time.

Appendix C2
Interview Schedule 2

We met 3 months ago while you were in hospital after you had had an operation on your hip.

1. How are you feeling now?

How have things been for you since we last met?

2. What can you remember about your time in hospital?

Prompt: What can you remember about the medical things that happened to you while you were in hospital?

Prompt: How do you feel people treated you while you were in hospital? You told me before.....

Prompt: When I spoke to you last time, you told me about some unusual experiences that you had while you were in hospital / some things you found strange. Can you tell me what you remember about these? (give prompt of specific example if can't recall)

3.1 How do you make sense of these memories of unusual experiences? / How real do these things seem to you now?

3.2 Some people who have had odd experiences after an operation on their hip think or dream about them afterwards. Can you tell me about how this has been for you?

Prompt: Please tell me about the last time you thought about these experiences?

Prompt: When you think about them, does it ever seem as if they are happening now?

Prompt: Do you ever find that thoughts about these experiences pop into your mind when you are not expecting them to?

Prompt: Do you ever dream about these experiences?

4.1 People sometimes notice "odd" things even after they have left hospital. What has your experience been since we last met?

4.2 Please tell me about the last time this happened?

4.3 Any other times?

4.4 Please tell me about how similar these things are to the things you noticed while you were in hospital?

4.5 Please tell me about any ways in which these experiences are different the unusual experiences you had in hospital?

5. When you think back to these experiences, how do they make you feel?

Prompt: People feel a variety of emotions – how have you felt?

6.1 Have you ever thought about why you have had these unusual experiences?

6.2 What do you think might have caused you to notice the odd things you talked about?

6.3 Lots of people see or hear odd things while they are delirious. Lots of people also believe things that they wouldn't normally believe. The things that they actually see / hear / believe are often different from person to person. The things that you saw / heard / believed might be very specific to you. Why do you think you had the experiences you had?

Prompt: some people link their experiences to things that have happened in the past. Other people talk about things that are particular to them.

7.1 What has your experience been of talking to other people about the unusual experiences you have described?

Prompt: Who?

Prompt: How did they react?

Prompt: How did you feel talking to them?

Prompt: Who would you have liked to talk to about these things?

Prompt: Why haven't you talked to them?

Prompt: How do you think they might react?

7.2 What explanations have you been given about why you have had these odd experiences?

Prompt: Who talked to you about this?

8. How have your experiences while you were in hospital affected the way you feel now?

Prompt: Ask specifically about delirium if only talk about hip fracture stuff

9. Some people think that these odd experiences will never happen again. Other people think they might have odd experiences again in the future. What do you think?

9.1 How do you feel about this? / How would you feel about the prospect of this happening again in the future?

10. What are your thoughts about going into hospital in the future?

11. 1 When you were in hospital, what things did you find unhelpful in helping you cope with unusual experiences?

11.2 What things did you find helpful in helping you cope with unusual experiences?

11.2 What other things might have been helpful in helping you cope with unusual experiences?

Prompt: What things do you think might help other people cope with similar experiences?

12. Can you tell me about anyone you know who has had similar experiences?

13. How have you found talking about these experiences with me?

Prompt: People have different emotions or feelings when talking about these things. What feelings do you have?

Thank you very much for your time.

DRS

Appendix D1

Temporal onset of symptoms	0	No significant change from longstanding behaviour
	1	Gradual onset of symptoms
	2	Acute change in behaviour
	3	Abrupt change in behaviour over 1-3 days
Perceptual disturbance	0	None evident by history or observation
	1	Feelings of depersonalisation/derealisation
	2	Visual illusions/misperceptions
	3	Markedly confused about external reality
Hallucination type	0	Not present
	1	Auditory hallucinations only
	2	Visual hallucinations
	3	Tactile, olfactory or gustatory hallucinations
Delusions	0	Not present
	1	Systematised, well organised and persistent
	2	New and not part of pre-existing disorder
	3	Transient, poorly organised, in response to mis-perceived stimuli
Psychomotor behaviour	0	No significant retardation/agitation
	1	Mild restlessness/tremulousness/anxiety
	2	Moderate agitation
	3	Severe agitation, needs to be restrained
Cognitive status	0	No deficit
	1	Very mild deficit due to inattention, worry etc
	2	Deficit in one major area eg memory
	3	Significant diffuse deficit
	4	Severe deficit
Physical disorder	0	None
	1	Presence of any physical disorder that may affect mental state
	2	Specific disorder implicated in altered mental state eg infection
Sleep-wake disturbance	0	Not present
	1	Occasional daytime drowsiness, mild night-time sleep disturbance
	2	Frequent napping, unable to sleep at night
	3	Drowsiness prominent
	4	Drifts into stuporous or comatose periods
Lability of mood	0	Not present
	1	Affect/mood altered over course of hours
	2	Significant inappropriate mood changes
	3	Severe disinhibition of emotions
Variability of symptoms	0	Symptoms stable, mostly present in daytime
	2	Symptoms worse at night
	4	Fluctuating symptoms over 24hr period
Total		

Appendix D2**THE GERIATRIC DREPRESSION SCALE****Instructions**

Please read each statement then circle the response which comes closest to how you have felt in the last **few days**. Do not take too long over your replies, your **immediate reaction** is more important than a long thought out response.

- | | |
|--|--------|
| 1. Are you broadly satisfied with your life? | YES/NO |
| 2. Have you dropped many of your activities and interests? | YES/NO |
| 3. Do you feel your life is empty? | YES/NO |
| 4. Do you often get bored? | YES/NO |
| 5. Are you in good spirits most of the time? | YES/NO |
| 6. Are you afraid that something bad is going to happen to you? | YES/NO |
| 7. Do you feel happy most of the time? | YES/NO |
| 8. Do you often feel helpless? | YES/NO |
| 9. Do you prefer to stay at home rather than go out and do things? | YES/NO |
| 10. Do you feel you have more problems with memory than most? | YES/NO |
| 11. Do you think it is wonderful to be alive now? | YES/NO |
| 12. Do you feel pretty worthless the way you are now? | YES/NO |
| 13. Do you feel full of energy? | YES/NO |
| 14. Do you feel your situation is hopeless? | YES/NO |
| 15. Do you think most people are better off than you? | YES/NO |

Appendix D3

BLESSED DEMENTIA SCALE¹

Changes in Performance of Everyday Activities	
1. Inability to perform household tasks	1 ½ 0
2. Inability to cope with small sums of money	1 ½ 0
3. Inability to remember short list of items, e.g. in shopping	1 ½ 0
4. Inability to find way about indoors	1 ½ 0
5. Inability to find way about familiar streets	1 ½ 0
6. Inability to interpret surroundings (e.g. to recognise whether in hospital, or at home, to discriminate between patients, doctors and nurses, relatives and hospital staff etc.)	1 ½ 0
7. Inability to recall recent events (e.g. recent outings, visits of relatives or friends to hospital, etc.)	1 ½ 0
8. Tendency to dwell in the past	1 ½ 0
Changes in Habits	
9. Eating:	
Cleanly with proper utensils	0
Messily with spoon only	1
Simple solids, e.g. biscuits	2
Has to be fed	3
10. Dressing :	
Unaided	0
Occasionally misplaced buttons etc.	1
Wrong sequence, commonly forgetting items	2
Unable to dress	3
11. Complete sphincter control	
Occasional wet beds	1
Frequent wet beds	2
Doubly incontinent	3
Changes in Personality, Interests and Drives	
12. No change	0
13. Increased rigidity	1
14. Increased egocentricity	1
15. Impairment of regard for feelings of others	1
16. Coarsening of affect	1
17. Impairment of emotional control, e.g. increased petulance and irritability	1
18. Hilarity in inappropriate situations	1
19. Diminished emotional responsiveness	1
20. Sexual misdemeanour (appearing <i>de novo</i> in old age)	1
21. Interests retained	1
22. Hobbies relinquished	1
23. Diminished initiative or growing apathy	1
24. Purposeless hyperactivity	1
Total	_____

¹ Blessed, G., Tomlinson, B.E. & Roth, M. (1968)

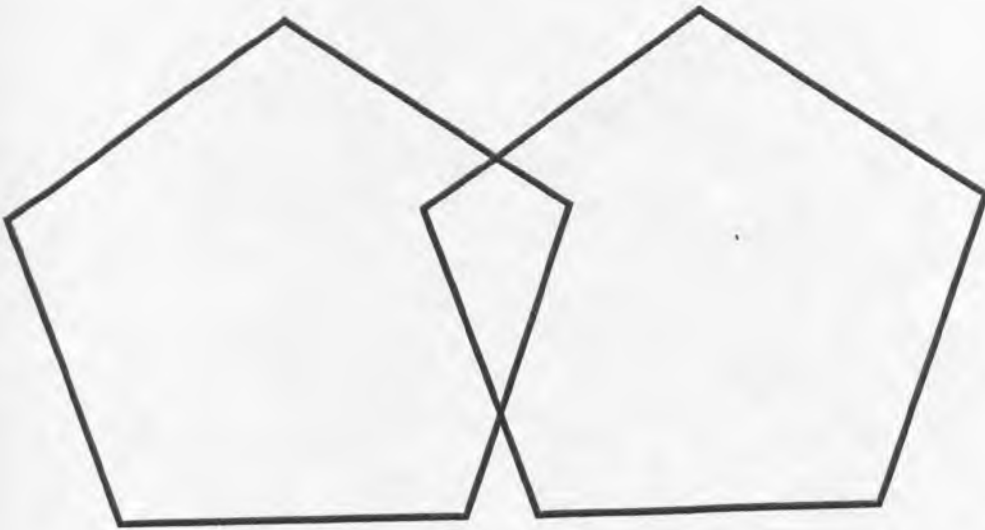
Standardized Mini-Mental State Examination (SMMSE)

Scoring sheet with instructions

I am going to ask you some questions and give you some problems to solve. Please try to answer as best you can.

		Score
1. (Allow 10 seconds for each reply)	Score	
a) What year is this? (accept exact answer only)	/1	
b) What season is this? (during last week of the old season or first week of a new season, accept either season)	/1	
c) What month of the year is this? (on the first day of new month, or last day of the previous month, accept either)	/1	
d) What is today's date? (accept previous or next date, eg: on the 7 th accept the 6 th or the 8 th)	/1	
e) What day of the week is this? (accept exact answer only)	/1	
2. (Allow 10 seconds for each reply)		
a) What country are we in? (accept exact answer only)	/1	
b) What province/state/county are we in? (accept exact answer only)	/1	
c) What city/town are we in? (accept exact answer only)	/1	
d) (In clinic) What is the name of this hospital/building? (accept exact name of hospital or institution only)		
(In home) What is the street address of this house? (accept street name and house number or equivalent in rural areas)	/1	
e) (In clinic) What floor of the building are we on? (accept exact answer only)		
(In home) What room are we in? (accept exact answer only)	/1	
3). I am going to name 3 objects. After I have said all three objects, I want you to repeat them. Remember what they are because I am going to ask you to name them again in a few minutes. (say them slowly at approximately 1 second intervals)		
Ball Car Man		
For repeated use:		
Bell Jar Fan		
Bill Tar Can		
Bull War Pan		
Please repeat the 3 items for me. (score 1 point for each correct reply on the first attempt). Allow 20 seconds for reply until, if subject did not repeat all 3, repeat until they are learned or up to a maximum of 5 times.	/3	
4). Spell the word WORLD. (you may help subject to spell world correctly) Say "now spell it backwards please". Allow 30 seconds to spell backwards. (If the subject cannot spell world even with assistance – score 0)	/5	
5). Now what were the 3 objects that I asked you to remember? Ball Car Man Score 1 point for each correct response regardless of order, allow 10 seconds.		/3
6). Show wristwatch. Ask: what is this called? Score 1 point for correct response. Accept "wristwatch" or "watch". Do not accept "clock", "time", etc. (allow 10 seconds)		/1
7). Show pencil. Ask: What is this called? Score 1 point for correct response, accept pencil only – score 0 for pen.		/1
8). I'd like you to repeat a phrase after me: "no if's, and's or but's" (allow 10 seconds for response. Score 1 point for a correct repetition. Must be exact eg: no if's or but's – score 0)		/1
9). Read the words on this page and then do what it says: Show subject the sheet with CLOSE YOUR EYES on it. If subject just reads and does not then close eyes – you may repeat: read the words on this page and then do what it says to a maximum of 3 times. Allow 10 seconds, score 1 point only if subject closes eyes. Subject does not have to read aloud.		/1
10). Ask if the subject is right or left handed. Alternate right/left hand in statement, eg: if the subject is right handed say "Take this paper in your left hand". Take a piece of paper – hold it up in front of subject and say the following:- "Take this paper in your right/left hand, fold the paper in half once with both hands and put the paper down on the floor". Takes paper in correct hand Folds it in half Puts it on the floor Allow 30 seconds. Score 1 point for each instruction correctly executed		/3
11). Hand subject a pencil and paper and say the following: Write any complete sentence on that piece of paper. Allow 30 seconds. Score 1 point. The sentence should make sense. Ignore spelling errors.		/1
12). Place pentagon design, pencil, eraser and paper in front of the subject. Say: copy this design please. Allow multiple tries until patient is finished and hands it back. Score 1 point for correctly copied diagram. The subject must have drawn a 4-sided figure between two 5-sided figures. Maximum time – 1 minute.		/1
Total score		/30

Close your eyes



CLINICAL PSYCHOLOGY TRAINING PROGRAMME

From the School of Medicine



15 Hyde Terrace
Leeds LS2 9LT UK

Telephone 0113 343 2732

Fax 0113 243 3719

clinical-psychology-training@leeds.ac.uk

Programme Secretaries:

Debby Williams

Caroline Hicks

WHAT IS IT LIKE TO HAVE DELIRIUM? – A RESEARCH PROJECT TO LOOK AT THE EXPERIENCES OF PATIENTS IN HOSPITAL FOLLOWING A HIP FRACTURE

You are invited to take part in a **research** project.

The Reason for the Research

A lot of people who break their hip become confused afterwards for a short time. We call this short-lived confusion “acute confusion” or “delirium”. There can be lots of different reasons for this. Sometimes people have odd experiences that they can’t explain, and these may be quite frightening.

We are interested in finding out what it is like for people who have delirium after a hip fracture. Knowing more about this experience will help hospital staff provide the best care for patients with delirium.

We would also like to talk to a number of people who have not been confused during their time in hospital to see how their experiences compare.

Rebecca Harding is the main researcher on the project, which is part of her training course in Clinical Psychology at the University of Leeds.

Please take time to read the information on this sheet before you decide if you would like to take part. You may also like to discuss it with other people before you make your decision.

Why have I been chosen?

You have been asked to participate in this study because you are in hospital with a hip fracture.



Do I have to take part?

It is up to you to decide whether or not to take part and you can decide to withdraw from the study at any time without giving a reason.

Deciding not to take part in the research will not adversely effect your care in any way.

What will happen to me if I take part?

During your stay in hospital, Rebecca will look at your medical notes and ask you, the nursing staff and your relatives some questions to see if you have been confused during your time in hospital. Rebecca will also ask you questions to see if you are depressed.

Rebecca would like to ask some people to talk to her about the experience of being in hospital. She will ask some people who are, or have been, confused while in hospital, and some people who have not been confused so that the different experiences can be compared. Rebecca would also like to ask people who have been confused to talk to her again in 3 months time. If Rebecca asks you to talk to her, you will be given more information about what it will involve. **Agreeing to Rebecca finding out if you have been confused does not mean you have to agree to talk to her about your experiences.**

What will happen to the information collected?

All information collected about you during the course of the research will be kept strictly confidential.

With your permission, Rebecca can pass on her findings to the medical staff to help them look after you in the best way.

If you agree to talk to Rebecca about your time in hospital, anything you say will be kept confidential and no-one will be able to identify you from the report of the interviews. The results of the project will be submitted to the University of Leeds as Rebecca's doctoral thesis and may be published in a scientific journal.

Further Information

If you would like more information about this study, please leave a message for **Rebecca Harding, Psychologist in Clinical Training** on **0113 343 2732**.

This study is being conducted by University of Leeds and Leeds Teaching Hospitals NHS Trust.

Appendix E2

**WHAT IS IT LIKE TO HAVE DELIRIUM?
PATIENT CONSENT FORM**

I have read the information sheet.

I understand the reason for the study and what will
happen if I take part.

I agree for the researcher to have access to my medical
notes where it is appropriate for the project.

I understand that I am free to withdraw from the study
at any time.

I understand that all information about me will be kept
strictly confidential.

I agree to take part in the research project.

Signed.....

Date.....

Print Name.....

Witnessed.....

Appendix E3**CLINICAL PSYCHOLOGY TRAINING PROGRAMME**

From the School of Medicine

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Programme Secretaries:

Debby Williams

Caroline Hicks

Follow-up Interview - Information sheet

**WHAT IS IT LIKE TO HAVE DELIRIUM? –
A RESEARCH PROJECT TO LOOK AT THE EXPERIENCES OF PATIENTS
IN HOSPITAL FOLLOWING A HIP FRACTURE**

The Reason for the Research

A lot of people who break their hip become confused afterwards for a short time. We call this short-lived confusion "acute confusion" or "delirium". There can be lots of different reasons for this. Sometimes people have odd experiences that they can't explain, and these may be quite frightening.

We are interested in finding out what it is like for people who have delirium after a hip fracture. Knowing more about this experience will help hospital staff provide the best care for patients with delirium.

We would like to talk to people soon after they have had their operation. We would also like to talk to people 3 months later to find out how things have been since then, and to reflect on their experiences of being in hospital.

Rebecca Harding is the main researcher on the project, which is part of her training course in Clinical Psychology at the University of Leeds.

Why have I been chosen?

While you were in hospital 3 months ago with a hip fracture you spoke to Rebecca about your experiences. We would like find out how things have been since then, and to find out your thoughts now about your experiences of being in hospital.



Do I have to take part?

It is up to you to decide whether or not to take part and you can decide to withdraw from the study at any time without giving a reason. Agreeing to talk to Rebecca while you were in hospital does not mean you have to agree to talk to her again. Deciding not to take part in the research will not effect your care in any way.

What will happen to me if I take part?

Rebecca will arrange a time to visit you at a place that is convenient to you (e.g. your home). She will talk to you about your time in hospital and how things have been since she last spoke to you.

What will happen to the information collected?

All information collected about you during the course of the research will be kept strictly confidential. The interviews will be recorded using a tape recorder and tapes will be kept in a locked cabinet until the study is finished and then destroyed. Your responses will be analysed together with the replies from other participants. No-one will be able to identify any individual from the report of the interviews. The results of the project will be submitted to the University of Leeds as Rebecca's doctoral thesis and may be published in a scientific journal.

Further Information

If you would like more information about this study, please leave a message for **Rebecca Harding, Psychologist in Clinical Training** on **0113 343 2732**.

This study is being conducted by University of Leeds and Leeds Teaching Hospitals NHS Trust.

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Debby Williams

Caroline Hicks

address

date

Dear

You may remember that I came to talk to you while you were hospital after the operation on your hip. This was for a research project that I am undertaking. It was really interesting to hear about your experiences. I am enclosing an information sheet to remind you of the details of the study.

As I explained at the time, I would also be interested to hear about how things have been for you since you have left hospital, and to talk about any thoughts you have about your time in hospital now you have been discharged. As when we talked while you were in hospital, this will just involve us having a conversation about how things have been for you, which I will tape record to help me remember what we've talked about. I'll also ask you a few questions at the end (as I did when you were in hospital). I am writing to arrange a time that I could visit you to do this.

I could come and visit you at your home, on

Date & Time

Please can you let me know if this is convenient for you, either by telephoning me on the above number or by completing the tear-off slip on the next page, and returning it to me in the envelope provided.



If this time is not convenient, or you would prefer not to be interviewed at home, please telephone me on the above number, or indicate on the tear-off slip and I can try to make arrangements for the follow-up interview which are most convenient to you.

If I have not heard from you by **date** I will try to contact you by telephone to arrange a convenient time.

Thank you for your time

Yours sincerely,

Rebecca Harding
Psychologist in Clinical Training

Please indicate as appropriate

- I am happy to be interviewed at my home on **date & time.**
- I would like to arrange a different time for the interview to take place.
Please suggest a date & time (not Monday) _____
- I would like the interview to take place at a location other than my home (*I will contact you by telephone to try to arrange this with you*)

Your Tel. No. _____
(It would be helpful to have your telephone number in case I need to contact you about the appointment).