

The delirium experience: what is the effect on patients, relatives and staff and what can be done to modify this?

Judith SL Partridge^{1,2}, Finbarr C Martin^{2,3}, Danielle Harari^{1,2} and Jugdeep K Dhese²

¹Division of Health and Social Care Research, Kings College London, London, UK

²Department of Ageing and Health, 9th Floor, North Wing, St Thomas' Hospital, London, UK

³Institute of Gerontology, Kings College London, London, UK

Correspondence to: J. Partridge, E-mail: judith.partridge@gstt.nhs.uk

Background: Delirium is a common clinical syndrome with significant associated mortality, morbidity and financial cost. Less is understood about the experience of delirium for the patient, their family and staff involved in their care.

Objective: This synthesis draws on qualitative and quantitative literature examining different populations (patients, relatives and staff) in different clinical settings (intensive care units, surgery and hospice care) to provide a clinical summary of the delirium experience from the perspective of patients, relatives and staff.

Design: A literature search was conducted in Ovid, MEDLINE, Embase, PsychINFO, British Nursing Index and Archive and PubMed between 1980 and 2011 using the terms 'delirium' combined with 'distress', 'recall', 'anxiety', 'depression', 'PTSD', 'experience' and 'patient education'. Articles were restricted to English language only.

Results: Evidence suggests that some patients recall delirium and that recollections are generally distressing. Distress may be greater in relatives witnessing delirium and is also reported in professional staff. This distress may result in longer-term psychological sequelae. Remedial action, such as explanatory information to patients and their families, may reduce distress and psychological morbidity.

Conclusions: A better understanding of the experience and psychological consequences of delirium will inform the development of appropriate methods of providing support and information to those at risk of delirium and their families or carers. Copyright © 2012 John Wiley & Sons, Ltd.

Key words: delirium experience; distress; psychological/psychiatric sequelae; relatives; staff; information provision

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Introduction

Delirium is a common syndrome with reported occurrence rates of 80% in medical intensive care units (ICU), 28% in patients following hip fracture and 22% in general medical inpatients (National Institute for Health and Clinical Excellence [NICE], 2010). Rates are also high in post-operative patients generally, cancer patients, care home residents and those in the terminal stages of life (Breitbart and Strout, 2000, Gagnon *et al.*, 2002, Siddiqi *et al.*, 2011). Risk factors for delirium are well described (Inouye, 1994, Inouye *et al.*, 1999, Litaker *et al.*, 2001). Strategies for successful delirium prevention are also reported (Inouye *et al.*, 1999, Marcantonio

et al., 2001, Vidan *et al.*, 2009) but are challenging to implement. This is important as delirium has an independent impact on mortality, morbidity and institutionalisation (Marcantonio *et al.*, 1994, Marcantonio *et al.*, 2000, Litaker *et al.*, 2001, Edelstein *et al.*, 2004) with a consequent bearing on length of hospital stay and significant economic implications (Rizzo *et al.*, 2001).

Less is understood about patients' experiences and recollections of delirium and any associated longer-term psychological morbidity. Furthermore, the psychological consequences of delirium can extend beyond the patient to impact relatives, carers and staff (Breitbart *et al.*, 2002, O'Malley *et al.*, 2008, Belanger and

Ducharme, 2011). The importance of the delirium experience has been recently highlighted in the NICE guideline on delirium, which advocates improved information provision to patients and relatives (NICE, 2010). The guideline encourages research into the impact of information provision on potentially reducing the severity and duration of delirium.

The literature examining the delirium experience is generally qualitative involving small numbers of patients across various populations (burns, orthopaedic/cardiac surgery, geriatric/palliative medicine and ICU). This qualitative evidence base has led to four quantitative studies describing the delirium experience (Jones *et al.*, 2001, Breitbart *et al.*, 2002, Bruera *et al.*, 2009, Grover and Shah, 2011). Although systematic reviews on specific aspects of the delirium experience exist (Davydow *et al.*, 2008, O'Malley *et al.*, 2008), there is a lack of a narrative synthesis to date comprehensively drawing on both qualitative and quantitative literature and examining different populations (patients, relatives and staff) in different clinical settings (ICU, surgery and hospice care).

This review aims to fill this gap by providing clinicians with a summary of how often patients recall delirium, what is recalled, how this impacts on distress levels in patients, relatives and staff and the longer-term psychological sequelae of delirium. The impact of information provision on reducing the negative consequences of delirium will also be discussed.

A literature search was conducted in Ovid, MEDLINE, Embase, PsychINFO, British Nursing Index and Archive and PubMed between 1980 and 2011 using the terms 'delirium' combined with 'distress', 'recall', 'anxiety', 'depression', 'PTSD', 'experience' and 'patient education'. Articles were restricted to English language only.

Do patients recall their delirious episode and what factors affect this recall?

Studies in the intensive care unit population

Delirium is common in the ICU (NICE, 2010). The 'ICU syndrome' and 'ICU psychosis' are terms used interchangeably to describe psychiatric symptoms observed in ICU patients. It is now thought that these syndromes are descriptions of delirium (McGuire *et al.*, 2000). Perhaps because of this ambiguity in terminology, studies involving ICU patients have suffered from a lack of consistent or robust diagnosis of delirium. Several studies report the proportions of patients who recollect factual events following ICU admission compared with those who recall confused, dreaming or delusional memories. The high incidence

of delirium within the ICU coupled with the similarity in reported experiences between ICU and delirious patients makes it likely that the recall of confused, dream-like or delusional memories reported in these studies does indeed relate to delirium.

The incidence of delusional or dream-like recollections in ICU survivors varies between about 20% and 75% (Kiekkas *et al.*, 2010). This wide variation may be explained by numerous factors including age, sepsis, sedation and deliberate under-reporting due to stigma from mental illness (Kiekkas *et al.*, 2010). Similarly, different rates of factual recall following ICU stay are reported (Jones *et al.*, 2001, Roberts *et al.*, 2007, Samuelson *et al.*, 2007). Unsurprisingly, factual recall is less common in those diagnosed with delirium during ICU admission (Roberts *et al.*, 2007). Reports of factual and delusional recall are relevant as delusional recall has been associated with symptoms of post-traumatic stress disorder (PTSD) (Jones *et al.*, 2001, Jones *et al.*, 2007, Granja *et al.*, 2008, Weinert and Sprenkle, 2008) and subsequent anxiety or depression (Jones *et al.*, 2001, Ringdal *et al.*, 2009, Kiekkas *et al.*, 2010).

Non-intensive care unit studies

Variable rates of delirium recall are also reported from non-ICU populations. Much of the literature is qualitative, and samples are small. Studies range from describing 'the majority' of patients having no recall of delirium (Duppils and Wikblad, 2007) to nearly 'all' patients interviewed reporting some recall of delirium (Andersson *et al.*, 2002, Cohen *et al.*, 2009). In the middle of this range, Schofield reported 'just over half' the patients recalling delirium in a small study of 19 patients (Schofield, 1997). Quantitative studies also report varying proportions of patients able to recall delirium. One study in 53 hospitalised patients of all ages reports only 28% of patients recalling some aspects of delirium (Grover and Shah, 2011). Other work in patients hospitalised with cancer describes delirium recall rates from 54% to 74%, respectively (Breitbart *et al.*, 2002, Bruera *et al.*, 2009).

It is not immediately clear why such variations in reported rates of delirium recall exist. In attempting to explain such variation, factors associated with recall of delirium have been assessed. A qualitative study examining patients 65 years and older who underwent hip surgery, perhaps unsurprisingly, showed that patients with a lower preoperative mini mental state examination score were less likely to recall the delirious episode (Duppils and Wikblad, 2007). Similarly, short-term memory impairment, delirium severity and perceptual

disturbances were all significantly associated with a lack of delirium recall in 101 patients who suffered from delirium whilst hospitalised with cancer (Breitbart *et al.*, 2002). Recall of delirium was not significantly different according to delirium subtype (hypoactive, hyperactive and mixed-type) (Breitbart *et al.*, 2002, Bruera *et al.*, 2009). Although this may seem surprising, both studies that reported this lack of association between delirium subtype and rate of recall used the Memorial Delirium Assessment Scale (Breitbart *et al.*, 1997) to systematically identify features of delirium subtype, adding credence to a lack of association between delirium subtype and recall rates. In one study, there was a univariate association between delirium subtype and recall, but this did not persist in logistic regression, suggesting that the relationship was confounded (Breitbart *et al.*, 2002).

What do patients recall of their delirious episodes?

Predictably, the patient's experience of delirium is predominantly described by qualitative research. Typically, research involves semi-structured interviews analysed using various methods including the phenomenological hermeneutic approach, qualitative content analysis and thematic analysis. Some studies assessed patients known to have been delirious during hospitalisation (Andersson *et al.*, 2002, Duppils and Wikblad, 2007, Harding *et al.*, 2008), whereas others interviewed patients after an ICU stay without reporting whether ICU delirium had actually been diagnosed (Laitinen, 1996, Granberg *et al.*, 1998, Magarey and McCutcheon, 2005). Although the lack of a robust delirium diagnosis seems problematic, many of the themes identified are similar, suggesting that although undiagnosed during the episode, the interviewed patients were likely to have suffered from delirium.

Themes in the recollection of delirium

Although contradictory experiences are reported, several common themes emerge. These include reality and unreality (Andersson *et al.*, 2002, Magarey and McCutcheon, 2005), day–night disorientation (Laitinen, 1996, Granberg *et al.*, 1998), clouding of thought processes or seeing through a fog or mist (Andersson *et al.*, 2002), strong emotions (anger, fear, insecurity and hopelessness) (Schofield, 1997, Duppils and Wikblad, 2007, Stenwall *et al.*, 2008a), lack of control (Andersson *et al.*, 2002, Fagerberg and Jonhagen, 2002, McCurren and Cronin, 2003), past and present clouding (Schofield, 1997, Fagerberg and Jonhagen, 2002, McCurren and

Cronin, 2003, Duppils and Wikblad, 2007) and misperceptions, hallucinations and delusions (Laitinen, 1996, Schofield, 1997, Granberg *et al.*, 1998, Andersson *et al.*, 2002, Fagerberg and Jonhagen, 2002, McCurren and Cronin, 2003, Duppils and Wikblad, 2007, Stenwall *et al.*, 2008a). These misperceptions, hallucinations and delusions commonly involve staff and other patients (Schofield, 1997, Crammer, 2002, Fagerberg and Jonhagen, 2002, McCurren and Cronin, 2003, Stenwall *et al.*, 2008a) and can also involve deceased family members (Magarey and McCutcheon, 2005). Communication difficulties are commonly reported with patients feeling they are not being listened to or understood (Granberg *et al.*, 1998, Andersson *et al.*, 2002, Duppils and Wikblad, 2007).

These themes are summarised in a subjective account written by a retired psychiatrist detailing his own experiences of delirium. In this account, he describes delusional recollections of surgery in other countries, attempts to 'dispose of him' when treatment had failed, deception by nursing staff and religious references to a Catholic priest. He recalls a lack of emotion and passivity, the experience of hearing but not understanding speech, misidentification of others and impaired concentration. This account neatly summarises the themes reported in the qualitative literature (Crammer, 2002).

Recollections involving family or staff

In general, the presence of family members appears beneficial to the acutely confused patient (Granberg *et al.*, 1998, Roberts *et al.*, 2007, Stenwall *et al.*, 2008a). Similarly when discussing the ICU syndrome, research suggests that the presence of a close family member can orientate the confused patient and help protect against emotions of fear, anxiety, loneliness or isolation (Eisendrath, 1980, MacKellaig, 1987, Morse, 1997, Granberg *et al.*, 1998).

Conversely, patients recall varied interactions with staff. The experience is either positive where staff are described as orientating, reassuring and kind or negative commonly involving perceptual disturbances or delusions (Laitinen, 1996, Granberg *et al.*, 1998, Crammer, 2002, McCurren and Cronin, 2003, Magarey and McCutcheon, 2005, Duppils and Wikblad, 2007). Examples of positive and negative experiences are quoted in the qualitative literature. These include patients reporting delusional recollections '...the nursing staff were going to kill me and sell my body parts overseas...' (Magarey and McCutcheon, 2005, p. 351), relief when the delirium resolved 'when I woke up next morning I

was so happy when I saw the nursing staff behave as usual and not as Nazi camp guards' (Duppils and Wikblad, 2007, p. 815) and reassurance from nursing staff 'when she (the nurse) was with me I felt I could rest for a while' (Granberg *et al.*, 1998, p. 302). The role of staff in influencing a patient's experience of delirium is reflected by one study where the nursing shift change was reported as a time of 'insecurity' (Granberg *et al.*, 1998).

What is the psychological and psychiatric morbidity attributed to the experience of delirium?

Distress

A study of hospitalised cancer patients conducted following resolution of delirium used a numeric scale (from 0 to 4 where 0 represents 'no distress') to record the degree of distress pertaining to the recall of delirium (Breitbart *et al.*, 2002). Of the 54% of patients who recalled delirium, 80% reported 'severe' distress relating to the recollection of the episode. The mean numeric distress rating was 3.2/4 in those patients who recalled delirium with delusional symptoms as the major correlate of distress (Breitbart *et al.*, 2002). These findings are replicated in another similar sized sample of cancer patients following delirium (Bruera *et al.*, 2009). This study used the same questionnaire and rating scale as Breitbart. The questionnaire asks patients who do not recall delirium how distressed they are that they lack memory of the episode. Overall, the median distress rating for patients in this study, regardless of whether they recalled delirium, was 2/4 (Bruera *et al.*, 2009). Median distress ratings in patients who did recall delirium were higher at 3/4 as were those in family members who observed patients whilst delirious, again with a median distress score of 3/4 (Bruera *et al.*, 2009).

Although intuitively we may assume that patients with hyperactive or mixed-type delirium may be more distressed than those with hypoactive delirium, in fact, the evidence suggests that the severity of distress is not affected by delirium subtype (Breitbart *et al.*, 2002, Bruera *et al.*, 2009). The only significant predictors of severity of distress within the delirious cancer patients studied were the presence of delusions (Breitbart *et al.*, 2002) and psychomotor agitation (Bruera *et al.*, 2009).

The relationship between short-term distress and longer-term psychological or psychiatric morbidity is not yet fully understood.

Post-traumatic stress disorder

In a recent systematic literature review, the median point prevalence of PTSD in ICU survivors was between 19% and 22% depending on differing diagnostic methods (either questionnaire-ascertained 'clinically significant' symptoms of PTSD or 'clinician-ascertained' PTSD) (Davydow *et al.*, 2008). This review included studies with follow-up periods from less than 1 month up to 2 years after ICU admission. The link between ICU delirium and the development of PTSD has been examined (Girard *et al.*, 2007, Roberts *et al.*, 2007). No significant association between delirium and PTSD has been shown; however, this may be due to inadequate diagnoses of delirium or a lack of statistical power (Davydow *et al.*, 2008). A lack of significant association between delirium and PTSD could be questioned because 'frightening or psychotic experiences' in ICU, both of which are commonly features of delirium, are consistently cited as predictors for the subsequent development of PTSD (Jones *et al.*, 2001, Jones *et al.*, 2003, Jones *et al.*, 2007, Davydow *et al.*, 2008). A short case series in transplant patients also reports delirium-associated delusions and hallucinations as a provocation for PTSD (DiMartini *et al.*, 2007). This potential association needs clarification in larger scale adequately powered studies using robust diagnoses both of PTSD and of incident delirium.

Anxiety and depression

Patients who suffered from delirium within 4 weeks of myeloablative hematopoietic cell transplantation displayed worse symptoms of depression and anxiety as well as greater fatigue than transplant patients without delirium (Fann *et al.*, 2007, Basinski *et al.*, 2010). These effects were seen initially after transplantation but persisted at 12-month follow-up. The impact of delirium on anxiety and depression also persisted following adjustment for numerous potential confounders including demographic factors, years of education, disease severity, comorbidity, prior chemoradiotherapy, complications of transplantation, use of glucocorticoids and pain score. Although scores of mental health functioning and cognitive assessment were undertaken at baseline, these are not listed in the table of confounders adjusted for in the analysis (Fann *et al.*, 2002, Fann *et al.*, 2007, Basinski *et al.*, 2010).

A literature review examining depression and anxiety after delirium reported a mean prevalence of clinically significant depressive symptoms, up to 2 years after a

delirious event, of 31% (range 4–47%) (Davydow, 2009). Lifetime prevalence of psychopathy within this study was quoted at between 35% and 67% (with depression +/- dementia included together). No data on comparative rates of depressive symptoms in an age-matched population were cited in the paper. However, for comparison purposes, the National Health and Nutrition Examination Survey data (2005–2008) reported a prevalence of 20.1% of adults with depressive symptoms according to the Patient Health Questionnaire-9 (PHQ-9) (Shim *et al.*, 2011). It was not possible from this work to attribute depressive symptoms directly to the delirium, and the author acknowledges that this psychological morbidity may be due to other factors, for example, the treatment of delirium (Davydow, 2009). As with the correlation between PTSD and recall of delirium, the association between anxiety, depression and delirium needs further exploration.

What effect does delirium have on patient's relatives?

The impact of observing delirium on the relatives or carers of patients is significant. A qualitative study used content analysis to describe distress in the relatives of terminal care patients who had suffered from delirium and found that 70% of families expressed distress at observing delirium in their relatives (Namba *et al.*, 2007). This distress was reported in relation to 'guilt', 'anxiety and worry', 'helplessness' and 'exhaustion' (Namba *et al.*, 2007). Similar findings are reported by another study examining the relatives of patients with advanced cancer who described their experiences as 'stressful', 'terrible', 'frustrating' and 'scary' (Cohen *et al.*, 2009). Notably though, those who had expected 'confusion' found the experience less distressing. Although it can be difficult to disentangle the distress related to the observation of delirium and the distress related to terminal illness, the findings of these studies are substantiated by other qualitative work using a descriptive phenomenological approach in non-terminal patients (Stenwall *et al.*, 2008b). Relatives in this work reported feelings of 'loss', 'mistrust' and 'insecurity' when dealing with the unfamiliar behaviour of a familiar person with an acute confusional state (Stenwall *et al.*, 2008b).

Not only is distress reported by a significant proportion of those families who observe delirium but also the degree of distress they report is considerable (Breitbart *et al.*, 2002, Bruera *et al.*, 2009). Seventy-six per cent of spouses or caregivers of cancer patients with delirium rated their distress at witnessing delirium as

'severe' (Breitbart *et al.*, 2002). These spouse/caregiver ratings of distress were higher than those reported by the patients who had suffered the delirium (mean numeric distress ratings of 3.75/4 in relatives and 3.2/4 in patients) (Breitbart *et al.*, 2002).

A study of 200 unpaid caregivers of patients with advanced cancer assessed generalised anxiety in caregivers in association with caregiver-observed delirium/confusion in the patient (Buss *et al.*, 2007). The reported incidence of generalised anxiety amongst carers was 3.5%. Caregivers who perceived the patient to have recently suffered from delirium were 12 times more likely to meet criteria for generalised anxiety than those who had not observed delirium or confusion (Buss *et al.*, 2007). This relationship persisted after adjusting for caregiver burden, suggesting that carer anxiety is not solely related to the increased demands of care in patients with delirium.

Family members of patients recovering from an ICU stay are at risk of developing PTSD (Jones *et al.*, 2004, Azoulay *et al.*, 2005, Griffiths and Jones, 2007) with incidence rates quoted at 49% in one study (Jones *et al.*, 2004). It is probable that PTSD in relatives relates to the trauma of a relative's critical illness and not solely to the observation of delirium. However, the distress caused to relatives by observing delirium coupled with the frequency of delirium in ICU patients suggests that delirium may be a potential contributor to the subsequent development of PTSD.

What effect does delirium have on staff?

It is acknowledged that caring for a patient with delirium can also impact negatively on staff. Most of the work examining this explores the impact of delirium on nursing staff as they tend to be most frequently and closely in contact with patients. Two literature reviews examining the effect of delirium on nursing staff summarise the themes identified in the qualitative literature (O'Malley *et al.*, 2008, Belanger and Ducharme, 2011). These include 'stress due to the unpredictability of delirium and workload', 'uncertain situations', 'issues of safety', 'patients keeping a distance or being suspicious of nurses', 'difficulties reaching patients', 'deciding when to be flexible and when to be in control', 'barriers such as the care environment not meeting needs of older adults' and 'understanding their experiences' (O'Malley *et al.*, 2008, Belanger and Ducharme, 2011). Breitbart *et al.* (2002) surveyed 101 nursing staff involved in the care of cancer patients with delirium and reported that 73% suffered severe distress with a mean distress score of 3.09/4 on a numeric

scale. The strongest predictors of nursing distress were delirium severity and perceptual disturbances (Breitbart *et al.*, 2002). In contrast, another study surveyed the impact of delirium on bedside cancer nurses, advanced nurse practitioners and palliative care physicians and reported a very low mean distress rating of 0/4 (Bruera *et al.*, 2009). The discrepancy between the results of these two studies, examining similar staff populations, is not easily explained. The authors of the most recent paper suggest several potential explanations for this observed difference (Bruera *et al.*, 2009). These include possible bias from surveying only daytime nursing staff (delirium may be worse at night-time or staff may feel more isolated at night-time), better symptom control in their patient population reducing the distressing impact on attending staff or the impact of training and support for bedside staff in minimising distress (Bruera *et al.*, 2009). Overall, however, when taken in context of the themes identified in the qualitative literature, it appears that managing patients with delirium is a stressful event for nursing staff. It is not yet fully understood whether and how education and training could minimise the distress attributed to professionally caring for a patient with delirium.

What is the role of information provision in reducing delirium and the associated negative sequelae?

Provision of information after the event

Intensive care unit diaries summarise events during an individual patient's ICU stay in lay terminology and are designed for the patient to read once they have recovered. These diaries have been shown in a randomised controlled trial to reduce psychological morbidity and decrease the incidence of new PTSD following ICU stay (Jones *et al.*, 2010). On the basis of expert opinion (DH and Modernisation Agency, 2003), many UK hospitals now run ICU follow-up clinics to identify ongoing physical and psychological issues affecting patients after intensive care treatment. The evidence base for ICU follow-up clinics is under review at present (Cuthbertson *et al.*, 2007). Similarly, the concept of 'debriefing' patients after a delirious episode is suggested by O'Malley *et al.* (2008). Such a 'debrief' following an episode of delirium may involve explanation of delirium, reassurance regarding recovery, information on reducing the risk of future recurrence of delirium and written information designed for patients and their relatives. At present, there is

insufficient evidence to support debriefing after delirium, but this remains a possibility for future research.

Provision of information prior to the event

Other work has examined the impact of pre-emptive information provision on reducing adverse delirium-related outcomes. A quasi-experimental study published 30 years ago tested the hypothesis that preoperative education about the possibility of unusual sensory or cognitive experiences (common in post-operative delirium) would reduce the occurrence of these experiences or allow for better coping strategies (Owens and Hutelmyer, 1982). Sixty-four patients undergoing cardiac surgery were consecutively assigned to intervention or control groups. A researcher discussed the possibility of developing post-operative perceptual disturbances, impaired concentration and cognitive difficulties with the intervention group. In post-operative interviews, there was no significant difference in the occurrence of 'unusual experiences' between the control and experimental groups. However, the intervention groups reported feeling significantly more 'comfortable' than the control groups during these unusual experiences (Owens and Hutelmyer, 1982). Notably, this study did not use a DSM-IV diagnosis of delirium and simply reported unusual perceptual disturbances. Although randomisation and formal delirium diagnosis would make this work more robust, it should pave the way for further studies assessing the role of pre-emptive information provision in reducing delirium-related distress.

Impact of information for patients

The qualitative literature consistently reports that patients following hip surgery and ICU admission desire information about symptoms of delirium (Laitinen, 1996, Magarey and McCutcheon, 2005, Duppils and Wikblad, 2007). Patients reported the importance of knowing that unreal experiences were common (Granberg *et al.*, 1998) and stated that knowledge about events and plans for their ongoing care helped them to feel safe and reassured (McCurren and Cronin, 2003, Stenwall *et al.*, 2008a). In addition, patients who experience delirium with perceptual disturbances are reluctant to mention this to staff (O'Malley *et al.*, 2008). This raises the need for training regarding delirium for staff working with older or at-risk patient groups. Staff should be taught to proactively question patients regarding perceptual disturbances and other symptoms of delirium. This may

facilitate the effective provision of information in a timely manner to both patients and their relatives.

Impact of information for families

Similar findings are seen in studies focussing on the role of communication in the families of patients with delirium (Morita *et al.*, 2007, Namba *et al.*, 2007, Cohen *et al.*, 2009). A qualitative study interviewed bereaved family members of cancer patients who had developed delirium at the end of life and led to the proposal of several strategies to reduce the distress associated with witnessing delirium (Namba *et al.*, 2007). These strategies provide a framework for effective communication for health care staff caring for delirious patients. They include 'respecting the patient's subjective world', 'treating the patients the same as before' and providing 'information support' (Namba *et al.*, 2007). The effects of information provision were studied in the family caregivers of patients suffering from delirium in a hospice (Gagnon *et al.*, 2002). A psychoeducational intervention involving nurse-led discussion and a brochure explaining delirium was evaluated using a before and after study. Prior to receiving the intervention, family members did not know what delirium was or that it could be treated (Gagnon *et al.*, 2002). The families receiving the intervention felt more equipped to make decisions than those receiving 'usual care', and overall, participants felt that family caregivers should be proactively educated about delirium (Gagnon *et al.*, 2002). Notably though, 2 weeks after the death of the patient, 24.3% of relatives did not recall having received the nursing intervention (these relatives were significantly older). The importance of 'treating the patient as before' was also highlighted by Stenwall *et al.* (2008b) who concluded that the relative's knowledge of the patient should inform the style of communication used and should be tailored to the individual patient encounter.

Limitations of this review

No large-scale studies exist describing the delirium experience or how to effectively ameliorate the impact of the condition. In terms of generalisability to adult patients as a whole, the literature in this field is over-represented by studies examining intensive and palliative care patients, and the heterogeneous nature of the populations studied may limit interpretation of the findings. However, despite these accepted limitations, the reported results are similar, suggesting

that regardless of underlying cause, the recall and experience of delirium for patients and the impact on relatives and professional carers display consistent themes.

By inclusively describing results from methodologically different studies in a diverse patient population, this review aims to provide a clinically meaningful summary of the delirium experience from the perspectives of patients, relatives and staff. The acknowledged shortcomings in both the published work and therefore this review should be addressed by future research in this field.

Future research

NICE delirium guidance (2010) highlights a lack of knowledge about the 'delirium experience' and advocates research into effective provision of information to patients and carers regarding delirium. This research should address whether the provision of information decreases the occurrence, duration or severity of delirium and whether there is an impact on patient and family delirium-related distress. NICE questions whether training informal family carers about delirium could improve early recognition of this condition and thus impact severity or duration. The answers to these questions may inform the process of assessment and counselling of patients at risk of delirium and their families. This has implications for numerous care settings including care homes, hospices, preoperative clinics and prechemoradiotherapy clinics where patients at high risk of developing delirium are commonly encountered. Similarly, the role of educational programmes aimed at improving knowledge and coping strategies in professional carers and nurses may serve to alleviate the distress caused to staff (Milisen *et al.*, 2004). This may have a secondary effect in improving explanation and reassurance to patients and their families during an episode of delirium.

Conclusion

In summary, we know from the evidence that patients may recall delirium and that this recall or the observation of delirium causes distress to patients, relatives and staff. Several common themes in the experience of delirium are identified in the literature including day-night disorientation, issues with communication difficulty and delusional thoughts. Furthermore, evidence of the longer-term psychological sequelae of delirium is emerging with the suggestion that delirium

may increase the subsequent incidence of symptoms of anxiety and depression.

The link between distress and psychological morbidity is incompletely understood and should be explored in future research. Although there are suggestions that information provision may help to reduce the distress attributed to delirium for both patients and relatives, this requires robust examination. Depending on the nature of the patient's illness and the urgency of presentation, proactive education for those at risk may be feasible, for example, in elective surgical patients. For other patients, pre-emptive education about delirium will not be possible because of emergency presentation, and in this group, the possibility of follow-up care for patients after delirium should be evaluated.

Pending better evidence but on the basis of the current literature, we advocate pre-emptive and post-event delirium education aimed at patients and relatives and including written material. Staff working with those at risk of delirium should receive training about the condition with the aim of both reducing the distress for patients and relatives and minimising the negative impact of observing delirium on staff.

Key points

- Regardless of subtype (hypoactive, hyperactive and mixed-type), delirium is often distressing for patients who recollect it.
- The experience of delirium may put patients at increased risk of psychiatric and psychological symptoms in the future.
- Distress at observing delirium in a relative can be greater than the distress reported by the patient themselves.
- Caring for patients with delirium can be stressful for professional carers.
- The role of information provision in reducing distress related to delirium should be researched in patients and their relatives.

Conflict of interest

None declared.

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