Distress in delirium: causes, assessment and management

Sophie T. Williams¹ · Jugdeep K. Dhesi^{1,2} · Judith S. L. Partridge^{1,2}

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Key Summary points

Aim Distress in delirium causes significant morbidity for patients and their relatives, but it remains under recognised.

Findings This review discusses the current literature regarding distress in delirium: its aetiology, available assessment tools and potential avenues for management.

Message The distress experienced in delirium has long-term psychological effects on patients and their carers, and requires greater understanding and acknowledgement in clinical practice.

Abstract

Purpose Delirium is a common clinical syndrome associated with increased physical and psychological morbidity, mortality, inpatient stay and healthcare costs. There is growing interest in understanding the delirium experience and its psychological impact, including distress, for patients and their relatives, carers and healthcare providers.

Methods This narrative review focuses on distress in delirium (DID) with an emphasis on its effect on older patients. It draws on qualitative and quantitative research to describe patient and environmental risk factors and variations in DID across a number of clinical settings, including medical and surgical inpatient wards and end of life care. The article provides an overview of the available distress assessment tools, both for clinical and research practice, and outlines their use in the context of delirium. This review also outlines established and emerging management strategies, focusing primarily on prevention and limitation of distress in delirium.

Results Both significant illness and delirium cause distress. Patients who recall the episode of delirium describe common experiential features of delirium and distress. Relatives who witness delirium also experience distress, at levels suggested to be greater than that experienced by patients themselves. DID results in long-term psychological sequelae that can last months and years. Preventative actions, such pre-episode educational information for patients and their families in those at risk may reduce distress and psychological morbidity.

Conclusions Improving clinicians' understanding of the experience and long term psychological harm of delirium will enable the development of targeted support and information to patients at risk of delirium, and their families or carers.

Keywords Distress · Delirium · Surgery

Introduction

Delirium describes a clinical syndrome comprising of disturbed cognitive function and altered consciousness with acute onset or fluctuating nature [1]. It is a common clinical syndrome, especially in older, acutely unwell, end of life or post-operative patients, with up to 22% of adult medical inpatients experiencing delirium [2]. Delirium contributes significantly to increased morbidity, both physical and psychological, as well as mortality, inpatient stay and healthcare costs [3–5]. There is growing interest in understanding the delirium experience and its psychological impact for

✉ Sophie T. Williams
sophie.1.williams@kcl.ac.uk

¹ Perioperative Medicine for Older People Undergoing Surgery (POPS), Department of Ageing and Health, St Thomas' Hospital, Westminster Bridge Road, London, UK

² Primary Care and Public Health Sciences, Faculty of Life Sciences and Medicine, King's College London, London, UK

patients and their relatives, carers and healthcare providers. This review focuses on distress in delirium (DID), its risk factors, assessment and management options and details current approaches in understanding this intersection of mental and physical health in the older population.

The literature investigating delirium experience spans a range of clinical environments, from hospital settings including the emergency department [6], intensive care unit (ICU) [7–11], inpatient oncology [12, 13], and surgical units [14–17] to community services such as nursing homes [18, 19] and hospices [20, 21].

While only some patients recall delirium, those who do and their relatives who witness it can experience significant distress and psychological morbidity. This review considers a broad definition of distress, including descriptions of anxiety, depression and PTSD resulting from a delirium episode. Examining associations between patient factors and features of delirium is useful for understanding who is at risk of DID.

Original research and review articles written in English were identified from Ovid, MEDLINE, PsychINFO, and PubMed databases between 1980 and 2019 using the terms ‘delirium’ and ‘distress’, ‘anxiety’, ‘depression’ or ‘PTSD’. These were then considered by the authors for relevance, content and impact. This is a narrative review, considering a broad range of articles relevant to understanding distress in delirium, and not a systematic review.

Causes of distress in delirium

Patient factors

Patient-specific factors influencing DID can be divided into risk factors common across healthcare settings and those specific to certain demographics or interventions.

The extent of critical illness and physiological insult contributes to DID. There is a high incidence of delirium in intensive care with figures reported up to 87% among patients surviving coma [22]. Multiple factors relating to critical illness, ICU admission and treatment are known to cause delirium: length of ICU admission, sedative use, analgesic control, infection with fever, renal failure, surgery [9, 23, 24]. Evidence shows that delirium in this setting is associated with psychological morbidity, including symptoms of Post-traumatic Stress Disorder (PTSD), anxiety and depression [10, 25], and that acute psychological reactions in ICU are a strong risk factor for psychological morbidity at 3 months [26, 27].

It is difficult to distinguish the contribution that delirium, as opposed to critical illness, makes to perception of distress and to disentangle these factors in the literature [28]. However, persistent delusional memories at 3 months are associated with development of PTSD, independent of illness

severity, suggesting that the presence of delirium may in itself be an independent cause of distress [10]. Similarly, worse functional status correlates with heightened DID. For cancer patients who recalled their delirium, reduced Karnofsky performance (< 30) positively correlated with distress severity [12].

While cognitive impairment, dementia and older age are risk factors for developing delirium [29], there is insufficient evidence as to whether these influence recall of delirium and therefore risk of DID. A qualitative study examining adults over the age of 65 undergoing hip surgery showed that patients with lower preoperative Mini Mental State Examination scores were less likely to recall the delirious episode [14]. However, this has not been supported by other studies [17, 12]. It cannot be assumed that because a patient is older, or has cognitive impairment, they will suffer any less from DID.

Delirium is common at the end of life. DID in palliative care or hospice settings has been explored most by characterising experience of distress by relatives and healthcare staff [21, 30, 31], in part because patients themselves do not survive to be able to recall their delirium or distress. Impact on carers is discussed later in this review.

Delirium factors

The phenotypic features of delirium and association with DID vary between clinical settings. This reflects heterogeneity in the patient groups and in the tools used to assess and label psychiatric presentations in delirium. In cancer inpatients assessed using The Memorial Delirium Assessment Scale (MDAS) [32], time/space disorientation, visual disturbances, delusions and psychomotor agitation were associated with increased distress. However only delusions [12] and psychomotor agitation [13] were independent predictors of severity of distress. In a postoperative cohort, delusions, abnormal thought processes, labile affect, language disturbance, agitation and disorientation as assessed using the Delirium Rating Scale (DRS) were associated with increased DID [17, 33], while orientation and thought disorder inversely correlated with extent of distress.

Intuitively, it might be thought that DID would differ between delirium subtypes. However, the available evidence suggests subtype of delirium (hyperactive, hypoactive or mixed) makes no difference to the extent of DID [12, 13, 17]. This has important clinical implications: hypoactive delirium is both more prevalent and at the same time underdiagnosed [16]. Patients with hypoactive delirium may not overtly display agitation, but it is likely they experience the same level of distress, and psychological morbidity as those patients with hyperactive delirium.

Severity of DID is associated with extent of recall of the delirium episode. While in some studies this has been

assumed, it has been shown explicitly for post-operative surgical patients, cancer patients and inpatients diagnosed with delirium [13, 17, 34]. Breitbart et al. [12] found that the rates of recall of delirium were inversely proportional to severity of delirium. ICU patients diagnosed with delirium during their admission, report lower rates of recall suggesting the episode of delirium may have been more severe [35]. Furthermore, delusional recall is a contributing factor to anxiety, depression and PTSD [10, 11].

Duration of delirium is an independent predictor of subsequent severity of global cognition and executive dysfunction [36]. Furthermore, delirium can have an impact on cognitive trajectory, both in patients with diagnosed neurodegenerative disease and older patients without any clinical evidence of neurodegenerative disease [37–39]. Duration of delirium is also associated with distress as shown in a mixed population of surgical patients followed up at 12 months [17].

Assessment of distress in delirium

Many assessment tools to identify distress have been developed: 45 different scales/scores exist for assessing depression and or distress in cancer patients alone [40]. However, few have been used in research or clinical practice of DID, as discussed below. The mixed aetiology of distress makes quantifying one single contributing factor impossible and so distress scores are often used in conjunction with pathology-specific assessment tools, depending upon the clinical area. Currently, there is no consensus on which assessment tool should be used to measure DID.

Measuring distress in clinical practice

The Hospital Anxiety and Depression Score (HADS) is an established assessment tool to examine self-reported symptoms of anxiety and depression among inpatients [41, 42], patients in the community and the general population [43], independent of physical symptoms. The HADS comprises 14 questions and has been used extensively in clinical practice and research. Tools with more than eight questions have been attributed better diagnostic accuracy and diagnostic validity. However, with more questions and time taken to complete, there is a recognised diminishing return: in one questionnaire survey, fewer than ten percent of oncologists were prepared to use full anxiety assessments, including HADS, in their clinical practice [44]. With respect to assessing DID, its length, focused nature and lack of specificity to delirium symptoms make the HADS less appropriate for assessing patients during an episode of delirium.

The Distress Thermometer is a brief self-assessment tool developed by the US National Comprehensive Cancer Network which asks patients to rate their distress on an ordinal

scale of 0 (no distress) to 10 (extreme distress) [45]. A score of 3 or more has been used as a marker of significant distress [46]. This prompts patients to complete a ‘problem list’, choosing ‘Yes’ or ‘No’ for a number of potential biological, psychological and social stressors. Its simplicity and validation against the established HADS in cancer has made it a widely used clinical assessment tool, as advised in the NCCN Distress Management Guideline with potential utility as a research tool. It has been used in the assessment of DID in older patients following surgery [17].

The Edmonton Symptom Assessment [47] and later ESAS-revised [48] is a self-reported patient questionnaire where symptom intensity is graded on an eleven-point linear scale across nine domains in advanced cancer (pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, shortness of breath, other). It is designed to be undertaken at various points through a patient’s cancer journey and was developed by palliative care physicians. While it has been used to assess severity of symptoms in delirious patients, including anxiety, it is not validated as a score of severity of DID.

Measuring distress in clinical research

The single delirium-specific distress assessment tool available is the Delirium Experience Questionnaire (DEQ) [12]. This score was developed to assess patients’ experiences after resolution of delirium and was used in conjunction with other scores (MDAS, Karnofsky Performance Status Scale) to assess predicting and correlating features for severity of DID. It was not, in its inception, validated against existing assessments scores for distress. The DEQ is a clinician-led questionnaire that asks six questions to patients regarding confusion, distress and recollection and a further two questions to relatives and care givers regarding their distress witnessing delirium. The score is given as either zero to moderate distress (0–2) or severe distress (3–4). Publications listed in Ovid databases MEDLINE(R), PsycINFO and PsycARTICLES until June 2019 included six further original research articles which use the DEQ [13, 34, 49–52]. Interestingly, none validate it against established anxiety/distress scales. The single publication to review responses to the ‘free text’ question 6 reported hallucinations, fear and anxiety as common themes, consistent with the literature, although no qualitative analysis has been published from this [34].

Other recognised scores of agitation/distress include the Horowitz’s Impact of Event Scale IES-6 [53], used mainly to understanding distress of events during ICU admission [54, 55], Psychological Distress Inventory [56], General Health Questionnaire 12 [57], Generalised Anxiety Disorder 7-item Scale (GAD-7) [58] and Structured Clinical Interview for the Diagnostic and Statistical Manual of Mental Disorders

Fifth Edition (SCID-5) [59], and while these have been validated as distress scores in oncology and palliative care, they are not common in the literature assessing DID.

Consequences of distress in delirium

Distress in delirium occurs during the episode of delirium, can persist for months or years and is associated with long-term psychological morbidity. DID is not limited to the patients themselves; relatives or carers witnessing patients' delirium can also experience significant distress.

Consequences for patients

Patients experience long term psychological consequences from DID. There is an established association between ICU-associated delirium and PTSD symptoms in ICU survivors [35, 60, 61]. No significant association between delirium and PTSD has been shown; however, this could reflect ambiguities in diagnosis of delirium and differing clinical assessment tools [62, 63]. Persistent delusional memories have significant functional consequences for ICU survivors: those who experience delusional memories are less likely to have returned to work 6–12 months after the episode. After accounting for confounders such as retirement and non-completion for this question, 67% of the non-delusional memory group had returned to work compared to only 15% of those patients who could recall delusions, $p < 0.01$ [64]. This trend was still present at 13–18 months, although it no longer presented a significant difference.

Consequences for relatives and informal carers

Relatives experience distress in witnessing family members with delirium. In one qualitative study, 70% of families experienced distress at observing delirium in their relatives [21], while a similar study conducted with relatives of patients with advanced cancer diagnoses described 'stressful', 'terrible', 'frustrating' and 'scary' experiences [13].

Severity of relative distress is associated with specific delirium and patient factors, namely hyperactive delirium, presence of brain metastasis, witnessing labile affect, language disturbance, thought process disturbance, motor agitation, loss of orientation and previous diagnosis of cognitive decline [12, 17, 30, 52]. Poor functional status was the only independent predictor patient-factor of spouse distress [12]. There is evidence to suggest that overall severity of the delirium witnessed also contributes to relative distress, although only identified among small numbers of participating relatives [12, 17].

Importantly, relatives' degree of distress can be higher than those reported by the patients themselves, and can

cause relatives long term psychological harm. Buss et al. undertook structured interviews among a cross sectional of 200 caregivers of patients with delirium. Caregivers who perceived delirium in their relatives were 12 times more likely to develop generalised anxiety [65]. This relationship persisted despite accounting for carer burden and exposure to other stressful experiences. One study suggests that PTSD incidence among individuals whose relatives have survived an ICU admission was as high as 49%, although this most likely reflects a combination of relatives' experience of patients being critically unwell, as well as their fluctuating recovery complicated by delirium [11].

Consequences for healthcare staff

Professional carers and healthcare staff experience distress when caring for patients with delirium. Two comprehensive reviews examine the breadth of qualitative research into experiences of patient delirium by nursing staff, reporting 'stress due to unpredictability of delirium and workload', concern over 'issues of safety' and 'understanding [delirious patients'] experiences' [66, 67]. Delirium-specific features causing significant distress for nurses, consistent across the literature, include psychomotor agitation, inattention or disorientation [12, 13, 49, 52].

An association has been reported between the extent and severity of the delirium episode and level of nursing distress [12]. However, this does not generalise to nurses working during day time hours (possibly due to variation in staffing levels and patients' day-night sleep disturbance) or those with greater training in delirium management [13].

Management of distress in delirium

While there is a significant body of literature investigating both management and prevention of delirium, the existing evidence for managing DID is limited. Current research focuses on information giving about delirium, before, during and after the event, and involving relatives in these interventions.

Understanding delirium before it happens

Early research into delirium suggested that education about delirium, before delirium presents, reduces the associated distress [68]. 64 patients undergoing cardiac surgery were assigned to educational intervention delivered by a researcher, who explains perceptual disturbances, and changes in cognition and concentration common in delirium, or to a control group. In post-operative interviews there

was no significant difference in the occurrence of ‘unusual experiences’ between groups, but those who received the educational intervention reported significant differences in feeling more ‘comfortable’ during these episodes.

Information during episode

Giving information to patients with delirium can be problematic due to reduced concentration and cognitive function. In the absence of clear evidence that education during delirium reduces patient-related distress, the focus remains on post episode interventions. This relies on identifying who would benefit from an intervention, when this should be delivered and what such an intervention should consist of [66]. There is evidence to suggest that patients want more information about symptoms of delirium [14, 69, 70] and patients report that knowing about the delirium and plans for their care and helps them to feel safe and reassured [69]. Such themes could be incorporated into a post-episode delirium related distress intervention.

Reducing relative distress is also key to treating DID, which, as explored above, can be more extreme than that experienced by the patient themselves. Relatives and caregivers also want support and advice on how to respond to patients with delirium [70]. In their survey of relatives’ understanding of delirium, Bull et al. concluded that prior knowledge about delirium in caregivers may reduce their distress. However, any proposed educational intervention may need to be timed effectively in order to reduce distress: relatives given educational material at some point before or during a patients’ delirium episode were more knowledgeable about delirium, but had no difference in their perceived distress [71]. Communication aids, in conjunction with educational resources, may be relevant for reducing distress [21].

Information following the event

There is an established practice in ICU to compile abbreviated, de-jargonised clinical ‘diaries’ for patients to discuss at appointments following discharge. Jones et al. [10] showed in a randomised control trial that discussing diaries at one month can reduce the incidence of new PTSD following ICU stay. However, systematic reviews of the evidence base for these diaries show, in general, small cohorts with varying methodology and uncertain generalisation across all patient groups in the ICU [72–74]. One ‘pragmatic’ randomised control trial of nurse-led follow up showed no evidence of improved physical or psychological health at 12 months in the intervention group [75]. In the UK, the implementation of generalised outpatient ‘debriefing’ post ICU and critical care admission is founded on expert opinion [76]. The approach of diaries and debriefing has been suggested for

patients who have recovered from delirium [66]. While there remains insufficient evidence to generalise this to patients who have experienced delirium, regardless of the aetiology, in general this remains a possibility for future research in the management of DID.

There is clear need to improve patients’ understanding of delirium: at one year follow up, structured interviews with 49 cardiac patients diagnosed with post-operative delirium, showed that many of the patients did not identify with the diagnosis of ‘delirium’, yet described many features associated with delirium [77]. This highlights the importance of education around delirium, and reducing the associated stigma.

Qualitative research exploring the views of patients and relatives in order to co-design interventions to reduce DID found that patients and relatives themselves had clear views about potential interventions to minimise this distress (under review). These included discussions of postoperative delirium, with patients as well as in the wider public sphere, and the provision of specific information on the harm delirium could cause (risk and causes of delirium, the expected recovery from delirium etc.), delivered by a trained person.

Summary

This review summarises the risk factors, assessments and current approaches for understanding and managing DID, collating evidence from a number of healthcare settings. Both patient and delirium specific factor contribute to higher levels of distress. DID exists not only during the episode of delirium, but can persist for months and years and is associated with long term psychological morbidity. Similarly, DID is not limited to the patients themselves: relatives or carers witnessing patients’ delirium can also experience significant distress, sometimes more pronounced than for the patient themselves. When evaluating the severity of distress, a number of assessment tools have been developed. However, only a few have been validated and adopted in research and clinical practice, and there is no current consensus on which tool should be used. Interventions to reduce DID focus on information giving about delirium, before, during and after the event, and for patients and relatives. Future strategies will need to adopt systematic methods for identifying patients at risk of delirium and, provide information before and after the episode of delirium.

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Compliance with ethical standards

Conflict of interest On behalf of the authors, the corresponding author states that there is no conflict of interest.

Ethical approval This article does not contain any studies with human participants or animals performed by any of the authors.

Informed consent For this retrospective review, formal consent is not required.

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