

Research Article

Codesigning an Intervention to Minimise the Distress Related to Postoperative Delirium for Patients and Relatives; A Mixed Methods Stepwise Approach

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Abstract

Introduction: Postoperative delirium is common and causes distress in patients and relatives with potential impact on long-term psychological health. No standardised approach to minimising delirium related distress exists. This study describes a mixed-methods, stepwise approach to co-designing an intervention to minimise distress related to postoperative delirium.

Methods: Incorporated three inter-related studies: Systematic review and narrative synthesis; qualitative exploration of views of patients and relatives; Modified Delphi panel to co-design the intervention.

Results: Step 1: Two non-randomised comparative studies showed some benefit in improving relatives' knowledge through psychoeducational intervention, but concluded that these interventions did not minimise distress associated with delirium.

Step 2: Patients and relatives advised on the timing, content and staff who should be delivering an intervention to minimise delirium related distress.

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Step 3: Modified Delphi technique facilitated coproduction of an intervention based on step 1 and 2.

Discussion: The co-designed intervention includes targeted support for patients and relatives; structured input at key timepoints prior to, during and whilst recovering from delirium; a focus on psychological sequelae rather than purely educational content and finally recognition that the intervention should be provided by an individual with expertise across the perioperative pathway rather than a delirium or surgical expert.

Keywords: Intervention; Older surgical patients; Perioperative medicine; Postoperative delirium; Psychological distress; Relatives and carers

Keypoints

- Distress related to postoperative delirium is common and has psychological sequelae
- Patients and relatives desire interventions to minimise distress related to postoperative delirium
- A mixed methods approach can be used to codesign an intervention to minimise distress for patients and relatives
- A delirium distress intervention should be delivered at different timepoints in the surgical pathway to patients and their relatives
- The intervention should be delivered by a professional with expertise across the perioperative pathway rather than a delirium or surgical expert

Background

Delirium is a common postoperative complication with associated morbidity, mortality, increased length of hospital stay and higher rates of institutionalisation at hospital discharge [1-3]. The frequency of delirium varies between different surgical populations and is higher following emergency surgery [4]. Whilst the morbidity and mortality associated with delirium has been long acknowledged, the psychological sequelae of delirium are increasingly recognised [5]. Such psychological sequelae include distress and symptoms of anxiety and depression [6-9].

Delirium is not always recalled, but in those who do recall the episode, a higher frequency of distress is reported [8]. Associations are observed between the severity of distress and specific phenotypic features of delirium, including delusions, labile affect and agitation [8]. Furthermore, relatives also suffer distress from witnessing delirium, which can result in ongoing psychological consequences with up to a twelve fold increase in generalised anxiety reported [10].

Educational interventions for families regarding delirium can provide useful coping strategies [11-14] and improve confidence in managing delirium [12]. However, at present, there is no standardised intervention used in clinical care to minimise distress associated with postoperative delirium, for either patients or their relatives. Addressing

this commonly encountered challenge requires a co-designed and co-produced intervention involving the views of all stakeholders [7,15].

This study describes a mixed methods, stepwise approach to address the following aims and objectives:

Aim

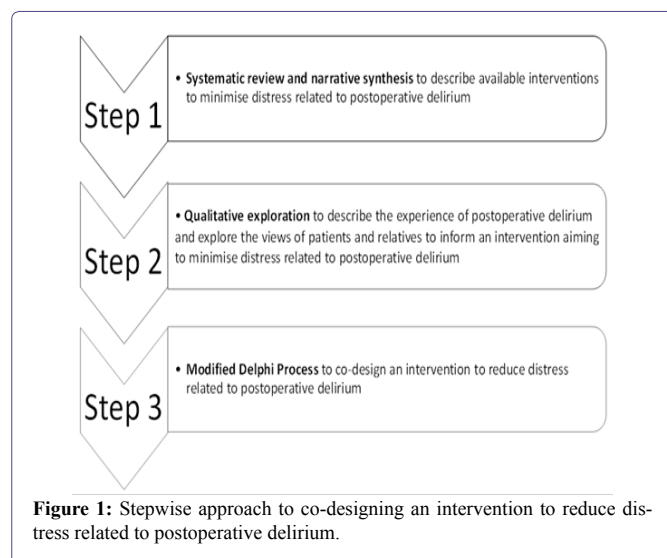
To develop an intervention to minimise distress related to postoperative delirium (POD) for patients and their relatives.

Objectives

- Describe available interventions to minimise distress related to delirium using a systematic review and narrative synthesis
- Qualitatively explore the views of patients and their relatives regarding interventions to minimise the distress related to POD
- Develop an intervention to reduce the distress related to POD using a Modified Delphi expert consensus process

Overall study design

A mixed methods, stepwise approach was used to develop an intervention to minimise POD related distress (Figure 1). This programme of work incorporated established methodologies at each stage to achieve the stated objectives. Through gaining information from three smaller, but inter-related studies, several potential research issues were mitigated. First, this allowed for stepwise accumulation of knowledge, second, the potential imbalance in power within the wider stakeholder group was addressed and third, co-production allowed development of a clinically feasible intervention.



Step 1: Systematic review and narrative synthesis

Aim: A systematic review was undertaken to describe evidence based interventions to minimise distress related to delirium.

Methods: A literature search was conducted in Medline, Pubmed and PsychInfo, with date limits between 1990-2019, using the terms ‘delirium’ combined with ‘distress’, ‘experience’, ‘education’, ‘information provision’, ‘intervention’ and ‘relatives’ and limited to English language (Appendix 1).

All identified abstracts were searched using the following predefined inclusion and exclusion criteria by two researchers (LD and TD). A third reviewer (JP) resolved discrepancies.

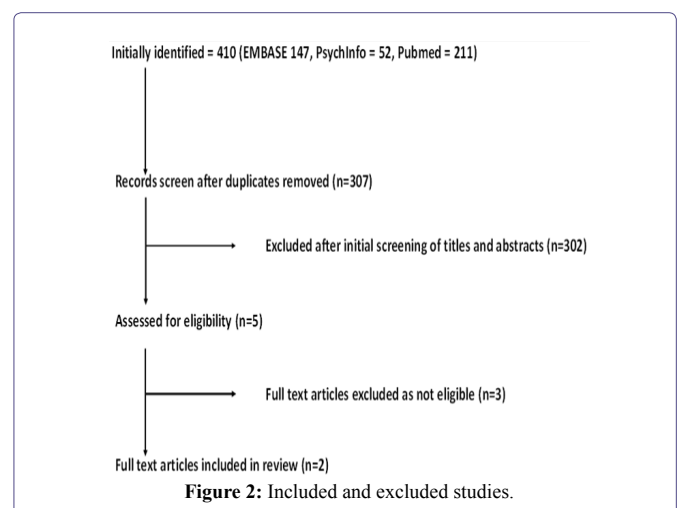
Inclusion criteria: Studies that trialled an intervention to reduce distress occurring after delirium. Experimental or quasi-experimental trials (randomised controlled trials, observational before-after studies, cohort studies, qualitative studies, quality improvement programs).

Exclusion criteria: Studies where the intervention aimed to reduce rates of delirium, not distress associated with delirium.

Case reports and case series: Due to a heterogeneous study population and inclusion of qualitative studies, narrative synthesis was chosen as the most appropriate methodology and registered ‘a priori’ on PROSPERO database (PROSPERO 2020 CRD42020127059). The narrative synthesis was undertaken in accordance with the Cochrane Consumers and Communication Review Group (CCRG) guidelines [16], the framework presented by the University of York [17] and the Guidance on the Conduct of Narrative Synthesis in Systematic Reviews [18]. Full text articles were assessed for risk of bias and given a quality score using an adaptation of the Critical Appraisal Skills Programme (CASP) checklist for cohort studies [19]. This tool consists of three sections to assess internal validity, the results and the relevance to practice (Appendix 2). The maximum score achievable was 12 with a higher score indicating lower risk of bias.

Results and discussion

Electronic searches identified 307 potentially relevant papers (Figure 2). Following abstract screening, five full articles were identified [5,12,14,20,21] of which three were subsequently excluded [5,20,21] as either no intervention was trialed or the intervention was targeted towards reducing the incidence of delirium, not distress associated with delirium (Table 1).



Two non-randomised comparative studies were identified for narrative synthesis. These trialled interventions designed for relatives of terminally ill patients with delirium. Relatives were provided with written information explained by a trained healthcare professional. Both papers showed that caregivers in the intervention group were more confident in caring for patients with delirium and showed better understanding of delirium [12,14].

Author/ Year/ Region	Study sample	Intervention	Study Design	Numbers	Summary of findings	Limitations
Otani et al., Japan [14]	Relatives of terminally ill patients with cancer Multicentre (3 palliative care centres)	Educational leaflet provided to bereaved family member.	Non-randomised comparative study	Intervention Group (n=235), of which analysis was performed (n= 113) Control Group (n=242)	Relatives sent questionnaire in the post at least 6 months after death of patient to assess their experience of delirium episode using a 5-point Likert-type scale. Intervention group showed better understanding of delirium and causes. No significant difference between levels of distress in family members between the two groups.	Due to moderate response rate may not representative of entire population. Weak study design compared to a parallel control study as control group was historical patients. Retrospective reporting may cause recall bias. Some family members failing to recognise delirium despite being diagnosed/ in contention of diagnosis of delirium. Confounding factor of relatives having profound emotional distress due to terminal diagnosis. Questionnaire tool was not validated or reliably tested.
Gagnon et al. [12] Canada (Quebec)	Relatives of terminal ill patients	Psycho-educational intervention in the form of verbal information and written brochure delivered by a trained nurse to family members.	Non-randomised comparative study	Intervention group (n=66) Control group (n=58)	Interviews were carried out with relatives 2-3 weeks following patients' death. Increased number in the intervention group reporting to know what delirium is. Intervention group had a better knowledge about the incidence of delirium and that the cause of delirium may be multifactorial. Intervention group felt more confident when caring for the patient with delirium. Ease of communication with other family members about delirium. Caregivers felt less distressed after learning what to do and what attitude to adopt with delirious patients. No difference in perceived mood between both groups.	Single centre, 15 bed palliative care unit and small study group not representative of a heterogeneous population. Potential confounding factor of distress related to terminal condition of relative. Short life span and short length of stay in the context of terminal illness Younger age group (mean 65.3 in control and 67.7 in intervention group).

Table 1: Summary of included studies.

Both studies were conducted in palliative care centres, with relatively small sample sizes potentially limiting the application to a more heterogeneous hospital population. Furthermore, as both studies targeted caregivers of patients with terminal delirium, differentiating between distress associated with delirium and distress associated with bereavement is difficult. As such there are no published data on interventions to minimise distress associated with POD for patients or caregivers.

Step 2: Qualitative study

This study is fully described elsewhere [7]. A summary is provided to illustrate the contribution of this study to the stepwise approach taken in the overall programme of work.

Aim: To qualitatively describe the experience of postoperative delirium and explore the views of patients and relatives in order to

inform the co-design of an intervention to minimise distress related to POD.

Objectives: To understand the views of patients and relatives regarding;

- The content of an intervention to be delivered to patients and their carers
- The timing of an intervention to be delivered to patients and their carers
- Who should deliver an intervention to patients and their carers?

Methods: Surgical patients and their relatives were recruited using a purposive sampling frame according to the inclusion and exclusion criteria below. Thematic analysis of individual semi-structured interviews involving patients and relatives was undertaken.

Inclusion criteria: Surgical patients aged over 18 years, following discharge from hospital recovering from POD, or carers and relatives of the patient who observed the episode.

Exclusion criteria: Functional limitation preventing attendance at outpatient interview, cognitive impairment severe enough to prevent consent to interview due to lack of capacity, terminal prognosis of less than three months and insufficient English to participate in interviews without need for a translator.

Results and discussion

Eleven patients and 12 relatives were recruited. The experience of POD had an emotional impact on both patients and witnessing relatives. Both found the experience distressing and believed that timely intervention to minimise this distress was necessary. Of the participants, 15 of 23 had not previously heard of the syndrome of delirium (eight patients, five relatives). Those who had prior knowledge of delirium felt more confident in managing the episode than those without. Both patients and relatives expressed a desire to pre-emptively receive information regarding POD, prior to its onset where possible. Relatives felt that adequate provision of information would help them develop better coping strategies to approach and communicate with the patient experiencing POD. With respect to the timing of professional support during and after the episode of delirium, participants suggested that communication should focus on relatives during the episode, and on both relatives and patients following resolution of the event. Both groups expressed a preference for face to face information provision by a single professional with an overview of the patient pathway. These findings were used in Stage 3 to inform the co-design of services aiming to minimise distress relating to POD.

Step 3: Modified Delphi process

Aim: To co-design an intervention to minimise distress related to POD using a Modified Delphi Process.

Methods: Modified Delphi is a methodology used to achieve group consensus where there is little or no definitive evidence. It involves a structured process where information is presented allowing experts to vote on the relevance of individual components to be included in the final design of an intervention or guideline [22,23]. This usually entails a survey completed across several rounds allowing participants to refine opinion through iterative discussion.

Themes identified during step 2 informed the development of a survey used to define important components of an intervention aiming to minimise the distress associated with POD. The survey included questions related to content, timing and delivery of the intervention for both patients and caregivers. The questionnaire was sent electronically to eight healthcare professionals. This expert panel was recruited to ensure representation from all relevant specialties and disciplines (appendix 3). In the context of limited published evidence, the use of the Modified Delphi method enabled cross-specialty and interdisciplinary consensus to be reached. Presentation of the patient and relative viewpoint from the study described in step 2, allowed full stakeholder involvement in co-design.

Results from Step 1 and 2 and results from survey round one, were collated and presented at the Delphi panel meeting together with wider literature from the field [8,9]. Adherent to the modified Delphi process, the expert panel discussed material prior to completing survey round two. Data saturation and agreement was reached at this point so the decision was made to omit the third round survey and instead to formalise the proposed co-designed intervention.

Results and discussion

The results of survey rounds one and two are summarised in table 2.

	Round 1		Round 2	
Question 1: What form should the intervention to minimise delirium related distress take?				
	Patient	Carer	Patient	Carer
Person	7/7	5/7 (+1 maybe)	6/7	5/7
Leaflet	7/7	7/7	5/7	6/7
DVD	0/7	0/7	1/7	1/7
Combination	3/7	2/7	4/7	4/7
Other	1 Video clips/e-learning; 1 website links		2 (online)	2 (online) 1 (support group)
Question 2: Who should deliver the intervention to minimise delirium related distress (if in person)?				
	Patient	Carer	Patient	Carer
Hospital Doctor	7/7	7/7	7/7	7/7
GP	2/7 (+1 maybe)	3/7 (+1 maybe)	3/7	2/7
Nurse	6/7	6/7	6/7	6/7
Other allied health professionals	5/7 (2 psychologist)	6/7 (2 psychologist)	4/7	4/7
Trained Lay person	0/7 (+1 maybe)	0/7 (+1 maybe)	0/7	0/7
Expert Patient	1/7 (+4 maybe)	1/7 (+3 maybe)	0/7	0/7
Question 3: What should be the optimal time for the delivery of the intervention to minimise delirium related distress?				
	Patient	Carer	Patient	Carer

On diagnosis	4/7	6/7	4/7	7/7
During the episode	4/7	6/7	4/7	7/7
On resolution whilst still in hospital	4/7	3/7 (+1 maybe)	5/7	4/7
On day of discharge	2/7	2/7	3/7	2/7
Interval post discharge	3/7 (+1 maybe)	1/7 (+2 maybe)	6/7 (+1 maybe)	3/7 (+1 maybe)
Question 4: What should the intervention to minimise delirium related distress be?				
	Patient	Carer	Patient	Carer
A single hospital contact with calling card	0/7	2/7	1/7	2/7
A single in-hospital contact followed by telephone/text/email/written contact	2/7	1/7	2/7	1/7
Multiple in-hospital contacts dictated by patient preference	5/7	5/7	5/7	4/7
A clinic at fixed time-point post discharge from hospital	1/7 (+1 maybe)	1/7 (+1 maybe)	2/7	0/7
An open access follow-up clinic post discharge	1/7	0/7	2/7	2/7
Other	GP, information leaflet, face to face explanation	GP	3/7 - 1 (phone) 1 (pre op)	3/7 - 1 (phone) 1 pre op
Question 5: What should the content of the intervention to minimise delirium related distress be?				
	Patient	Carer	Patient	Carer
An informal opportunity to discuss concerns, fears etc related to the episode of delirium	6/7	7/7	7/7	6/7
A structured review of the episode of delirium	3/7 (+2 maybe)	3/7 (+1 maybe)	3/7 (+1 maybe)	3/7 (+1 maybe)
Counselling	3/7 (+3 maybe)	1/7 (+2 maybe)	1/7 (+1 maybe)	1/7 (+1 maybe)
Cognitive behavioural therapy	1/7 (+2 maybe)	0/7 (+1 maybe)	0/7	0/7
Mindfulness	0/7 (+1 maybe)	0/7 (+1 maybe)	0/7	0/7
Question 6: Who should the intervention to minimise delirium related distress be delivered to?				
	Patient	Carer	Patient	Carer
Individuals	7/7	6/7	6/7	6/7
Groups	2/7 (+2 maybe)	3/7 (+1 maybe)	2/7 (+2 maybe)	1/7 (+1 maybe)
Both	2/7	2/7	1/7	1/7
Question 7: Should the intervention to minimise delirium related distress be tailored to the delirium subtype (e.g. hypo versus hyperactive)?				
	Patient	Carer	Patient	Carer
Yes	2/7	2/7	3/7	3/7
No	5/7	5/7	4/7	4/7

Table 2: Results from first and second round survey of Modified Delphi.

The resultant co-designed intervention is presented in figure 3.

Based on this programme of work, the proposed psycho-educational intervention to minimise delirium related distress should be delivered by a healthcare professional with experience in managing delirium and with an overview of the patient pathway. Four potential time-points for intervention delivery and the aim of each component of the intervention were defined:

Preoperative

The aim of the preoperative component of the intervention is to anticipate and mitigate delirium related distress in patients and relatives. This component is applicable to elective patients seen in preoperative assessment clinic and to emergency patients at risk of delirium but in whom delirium has not yet occurred. It should be delivered to both patients and relatives in person or over the telephone. The timing of this intervention will vary depending on whether the surgical presentation is elective (for example total hip replacement seen 3 months prior to surgery), urgent surgery (for example surgery

for colorectal cancer seen 10 days prior to surgery) or emergency surgery (for example surgery for hip fracture seen less than 24 hours prior to surgery).

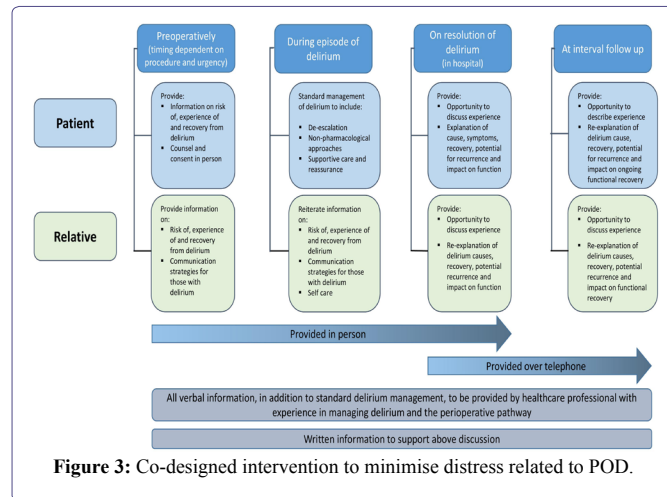
During delirium

The intervention delivered during the episode of delirium is designed primarily for relatives who have observed the delirium. It should ideally be delivered in person. During the delirium episode, patients should receive standard clinical care for delirium, including de-escalation strategies and non-pharmacological approaches, but the Delphi process suggested that this component of the proposed intervention should be targeted at relatives. This is due to the perceived inability of patients to assimilate useful information or benefit from counselling during an episode of delirium.

On resolution of delirium

This component of the intervention aims to 'make sense' of the episode of delirium and explore delirium related distress. It should be

delivered in person to both patients and relatives in hospital prior to discharge.



Interval follow up

The aim of the follow up component of the intervention is to allow reflection on the episode of delirium and understand and mitigate possible longer term distress and psychological sequelae. It is assumed that in the majority of cases, this component of the intervention will be delivered following discharge from hospital and could be delivered in person or over the telephone to both patients and relatives. If the hospital stay is protracted but no further delirium occurs, this component of the intervention could be delivered in hospital. Onward referral to psychiatry or memory services should be made if there are concerns about mood disturbance, symptoms of post traumatic distress syndrome or suspected underlying cognitive impairment.

Overall Discussion

This programme of work is the first to use a mixed methods, stepwise approach to develop a co-designed intervention aiming to minimise distress related to POD. Challenges to the development of such an intervention included the paucity of existing evidence from both professional and patient perspectives, a lack of current expert consensus or guidelines and an absence of implementation strategies aiming to minimise distress related to POD. Despite these challenges, delirium is common and the importance of identifying and managing distress related to delirium is increasingly recognised in national guidance [4,24]. In this paper, a stepwise approach using validated methodology at each stage was chosen, which facilitated an iterative process where each step built on knowledge gained from the former. Such an approach allowed synthesis of the limited available evidence, appraisal by a wide stakeholder group, and co-design of the proposed intervention. The designed intervention includes targeted support for both patients and relatives; structured input at key timepoints prior to, during and whilst recovering from delirium; an acknowledgement of psychological sequelae rather than delivery of purely educational content and finally a recognition that the intervention should be provided by an individual with expertise across the perioperative pathway rather than a delirium or surgical expert.

Such an intervention is in keeping with pathways developed for patients and families to manage distress following intensive care admission [25], cancer diagnosis or terminal disease [26]. Across these clinical areas, debate continues regarding the necessary components of psychoeducational delirium distress interventions. This includes who should receive such an intervention, the timing (for example at diagnosis, commencement of treatment, post-treatment period), the content (particularly regarding the balance between education and psychological support strategies), the method of delivery (including supporting resources) [4,27] and the personnel involved. The intervention should be targeted at patients at risk of postoperative delirium and their relatives. Identification of patients at risk will differ according to the elective or emergency setting. In the elective setting patients can be identified through the preoperative assessment process, and in the emergency setting patients should be screened for delirium risk at presentation. Qualitative work conducted in step 2 gave clear guidance on the timing of an intervention to minimise POD related distress from the patient and relative perspective. In keeping with the survivor clinic literature from the intensive care setting, a small number of patients and relatives felt that imposing follow up after delirium may worsen distress and therefore this component of the intervention would be offered rather than stipulated [28]. With respect to content, previous work has shown that although educational interventions improve knowledge, these approaches alone are insufficient to reduce distress [29]. For this reason a psychoeducational approach to the content is recommended; in addition to routine provision of information on the cause, treatment, duration and recovery of delirium, patients and relatives should receive information on communication strategies, disentangling of reality from unreality, future management and partnership health care. In terms of method of delivery, despite the promotion of technology based interventions [30], patients, relatives and the expert panel concluded that the intervention should be delivered face to face in this clinical scenario. Finally, in the context of POD, this study suggests that the intervention would be best delivered by an individual with an overview of the patient and the pathways as opposed to necessarily being the surgeon or delirium expert. This recommendation is based on the expressed views of patient and relatives and may relate to difficulties in disentangling the distress related to delirium from the negative psychological sequelae related to the surgical episode. As such, the call for the intervention to be delivered by a healthcare professional with an overview of the whole pathway is understandable and may guard against fragmentation in the provision of information and support [31,32].

Limitations of this programme of work should be acknowledged. There is the potential for bias both in the qualitative study and at the modified Delphi stage. The purposive sampling frame in step 2 aimed to mitigate bias through inclusion of patients and relatives from a varied background. The focus on the patient and relative perspective at stage 2 also resulted in presentation of rich data at step 3. Given this, an 'a priori' decision was made to conduct the modified Delphi group using a professional only panel to avoid an unrepresentative single patient voice and address the potential imbalance between patients and professionals. Despite the acknowledged limitations, this pragmatic approach adds to the existing literature through provision of a co-designed and co-produced intervention to minimise distress related to POD.

Conclusion

This programme of work resulted in a co-designed intervention aiming to minimise distress related to POD. The next step is to test the feasibility and effectiveness of this intervention in clinical practice including evaluation of communication between relatives and patients with delirium and lower rates of delirium related distress.

Conflict of Interest

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

Acknowledgement

Patients, relatives and Modified Delphi panel.

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Appendix

Appendix 1: Systematic review search strategy

The narrative synthesis was designed using the PICO framework considering the following components;

Population: Older population group >65years who experience delirium

Intervention: any intervention that reduces distress related to delirium for patients and relatives e.g., patient education and information provision

Comparators: Best standard delirium care

Outcome: Measure of how effective the intervention has been e.g., using standardised assessment tools including distress thermometer, HADS, interviews and feedback from patients, relatives and staff about their experience.

Search strategy used:

1. (exp delirium)
2. (Distress.mp [mp = title, abstract , keyword, original title, subject heading])
3. (Delirium adj2 distress)
4. (exp patient)
5. (carer/OR care giver/OR caregiver)
6. (relative)
7. 7 (intervention)
8. (Education*)
9. (Information*)
- 10.(information adj5 provision)
- 11.(1 AND 2)
- 12.(11 OR 3)
- 13.(4 OR 5)
- 14.(7 OR 8 OR 9 OR 10)
- 15.(12 AND 13 AND 14)

Appendix 2: CASP score for included papers

Author/Year/Region	CASP score
Otani et al., [14] Japan	6
Gagnon et al., [12] Canada (Quebec)	6

Appendix 3: Modified Delphi expert panel

Name	Profession	Affiliation
Ms Elizabeth Biswell	Research nurse	Guys and St Thomas' NHS Foundation Trust
Dr Duncan Forsyth	Consultant Geriatrician	Consultant geriatrician Medicine for Elderly, Addenbrooke's Hospital Cambridge
Dr Valerie Page	Consultant Intensivist	Intensive Care Unit, Watford General Hospital, West Hertfordshire Hospitals NHS Trust, Watford, UK Faculty of Medicine, Imperial College, London, UK
Ms Elizabeth Willis	Clinical Nurse Specialist Dementia and Delirium	Guys and St Thomas' NHS Foundation Trust
Dr Mark Kinirons	Consultant Geriatrician	Guys and St Thomas' NHS Foundation Trust
Dr Jim Bolton	Old Age Psychiatrist	Liaison Psychiatry Faculty Chair Consultant Liaison Psychiatrist St Helier Hospital, Wrythe Lane, Carshalton, Surrey
Dr Dorothy Wade	Clinical Psychologist	Critical Care Department, University College London
Ms Ana Babic-Ilman	Clinical nurse specialist	Perioperative medicine for Older People undergoing Surgery (POPS), Guys and St Thomas' Hospital
Professor Rowan Harwood	Palliative Care and	Professor of Geriatric Medicine, Faculty of Medicine & School of Health Sciences, University of Nottingham
Facilitators		
Dr Jugdeep Dhesi	Consultant geriatrician	Consultant geriatrician and lead for Perioperative medicine for Older People undergoing Surgery (POPS)
Dr Judith Partridge	Consultant geriatrician	Consultant geriatrician, Perioperative medicine for Older People undergoing Surgery (POPS)
Dr Catherine Meilak	Consultant geriatrician	Consultant geriatrician, Perioperative medicine for Older People undergoing Surgery (POPS)



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