

The experiences of caregivers of patients with delirium and their role in its management in a palliative care setting

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Background

Delirium remains the most common and distressing complication in patients with advanced cancer. Up to 62% of patients during a palliative care inpatient admission and up to 88% of patients in the days or hours preceding death experience delirium¹.

Aims

- 1) To explore the experiences of caregivers of patients with delirium.
- 2) To explore the role of caregivers in management of delirium.
- 3) To explore evidence for interventions to improve support for caregivers and to help caregivers to support the patient.

Method

An integrative review was undertaken. Twenty five papers were included in the final review. Four databases were searched using the terms:

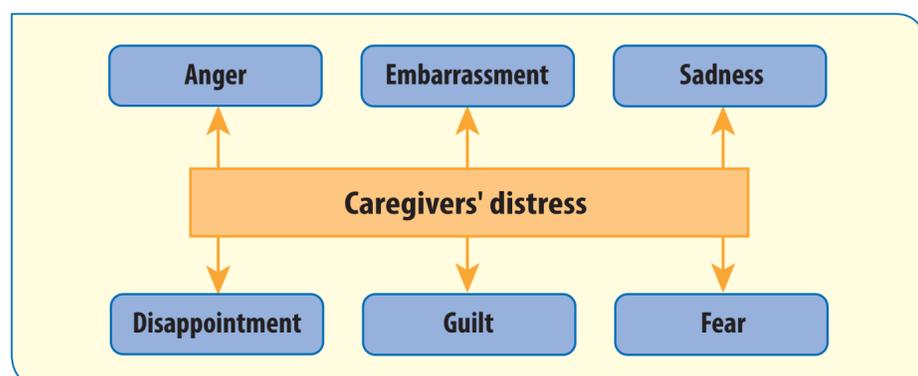
- Delirium
- Terminal restlessness / agitation combined with;
- Family / carer / caregivers

Results

1) Distress is common in caregivers of patients with delirium.

- Distress is sometimes greater in caregivers than in patients themselves.
- There are a range of distinct negative emotions which can be experienced by caregivers during patient delirium.
- Deteriorating relationships are common when delirium occurs.

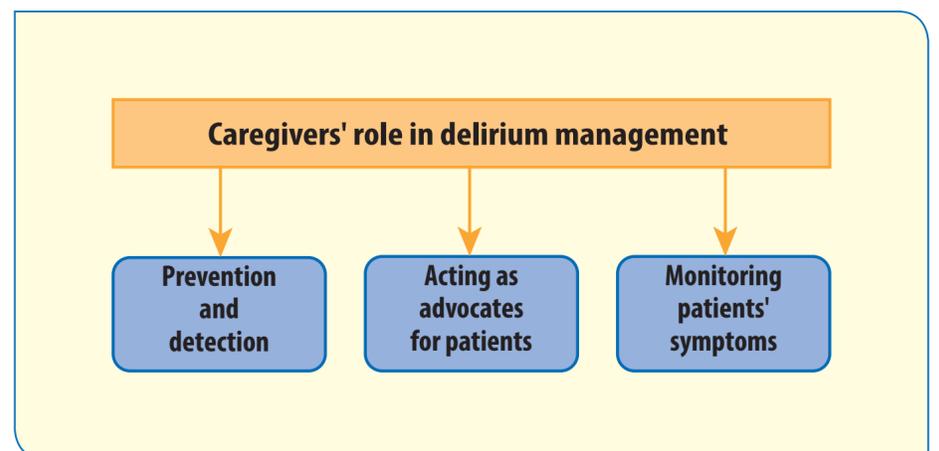
Figure 1: Distress and negative emotions experienced by caregivers during patient delirium.



2) Caregivers could potentially play an important role in the management of delirium in palliative care settings.

- Recent studies suggest that caregivers could potentially play a role in the detection of delirium; symptom monitoring and acting as advocates for the patient who is experiencing delirium.

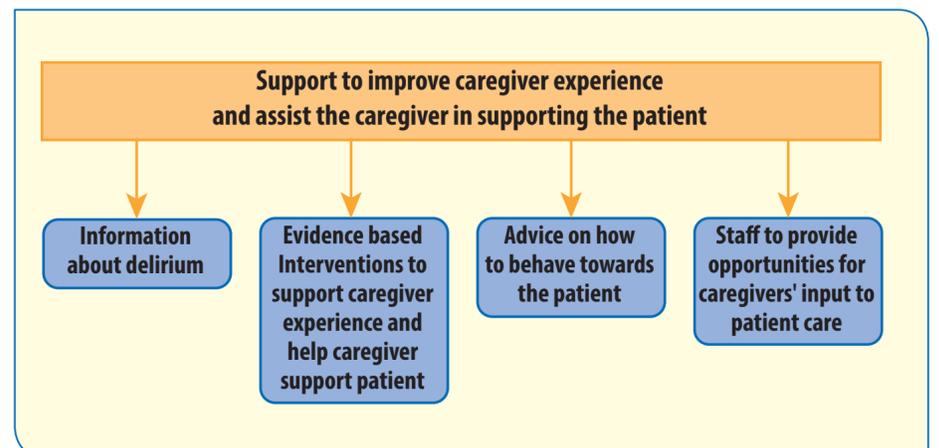
Figure 2: The role of caregivers in management of delirium.



3) There is a need for evidence based interventions to improve support for caregivers of patients with delirium, and to help the caregiver support the patient during delirium.

- Caregivers would like information and advice on how to help the patient with delirium and are keen to input into patient care.
- Interventions such as information leaflets in conjunction with a discussion with a staff member are effective in improving caregiver wellbeing and confidence in helping patients with delirium.

Figure 3: Support to improve caregiver experience and assist the caregiver in supporting the patient.



Conclusions

- High levels of distress and negative emotions are experienced by caregivers of patients with delirium.
- Many caregivers would like an opportunity to play an active role in the management of delirium.
- There is a need to design and test new interventions to help caregivers support the patient experiencing delirium and to improve the wellbeing of caregivers themselves.



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