

Manchester conference

How can carers be supported better at end-of-life? A mixed methods study to identify recommendations for change in organisational structures/processes.

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Background

Carers play a vital role in supporting patients at end-of-life (EOL). EOL care policy promotes comprehensive person-centred assessment/support for carers, but without a clear implementation strategy this will only remain an aspiration.

Aim

To develop recommendations for organisational structures/processes required for implementation of comprehensive person-centred comprehensive assessment/support for carers in EOL practice.

Methods

1) Secondary analysis of qualitative data on implementation in 36 services to identify factors facilitating/hindering implementation. 2) Expert consultation (focus groups with 19 lead practitioners/hospice managers) to review Stage-1 findings and develop draft recommendations. 3) Wider stakeholder consultation-two professional workshops (23 participants: hospice, hospital, community, policy and academics), online survey (62 participants) and two carer workshops (nine participants) to finalise recommendations.

Results

Comprehensive, person-centred carer assessment/support requires whole-systems change; a cultural shift at practitioner and organisational level. Ten recommendations identify key structures and processes not normally met by current provision:

- Consistent identification of carers within the care setting
- Demographic and contextual data on who the carer is and their situation
- A method/protocol for assessing carers and responding to assessment
- A recording system for carer information (separate from patient data)
- A process for training staff *about carer assessment/support*
- Available time/workload capacity *for carer assessment/support*
- Support from senior managers
- Role models/champions
- Pathways for communication *about carer assessment/support*
- Procedures for monitoring/auditing processes and outcomes *of carer assessment/support*

Implications

Comprehensive, person-centred carer support requires radical change, at different organisational levels. Carers' fit within service provision also urgently needs clarification. Our 10 recommendations outline necessary building blocks to achieve this change.

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