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'BATTLING ON' AND 'BLINKERED': CARER EXPERIENCES OF HOME BASED CARE AT THE END OF LIFE

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Introduction The physical care needs of patients approaching the end of life are considerable and require specialist knowledge and skills amongst those who care for them. However, when hospice patients are discharged back home families often express concern as they receive no formal guidance on practicalities of physical care and instead adopt a 'trial and error approach' to palliative care. This is not only problematic for the patient but also impacts upon carer wellbeing.

Aims and Methods To explore the experiences of carers and health professionals of end of life care provided in the home setting by informal carers. To explore views on the information and training needs of carers and how these might feasibly be addressed via interventions. Two focus groups with hospice based nurses and two groups with carers/ former carers of patients at the hospice. Discussions explored experiences of, and views on, the challenges of providing care in the home setting, the information and training needs of carers, and possible interventions. Results: Thematic analysis of the data has indicated knowledge gaps and concerns amongst carers relating to practical care tasks and uncertainty over what support services are available and when and where to get help. The data also provides examples of how such concerns impact upon carer wellbeing and adaptation, and how carer and patient identities influence service use.

Conclusion Carers experience a complex set of challenges, needs and barriers when providing end of life care, with implications for patient care, carer wellbeing and interventions which provide support to carers.