Introduction:
In the UK, people who provide a home-based care for someone with a moderate to advanced dementia have reported a feeling of an internal conflict due to not knowing what to do especially towards the end of life. Studies show that this experience is called ‘moral distress’ and has also been reported by carers within other settings. The experiences of people providing home-based care are yet to be investigated.

Data and Methods:
To elicit accounts from informal/family caregivers who currently provide home-based care to people within the moderate to advanced stages of dementia (GDS Score ≥ 5), or who had done so within the previous 6 months. Fifteen (n=15) voluntary participants recruited from community-based support groups and via Joint Dementia Research (JDR). Single-time interviews of ≤ 2hrs within a domestic home-setting. Narrative analysis guided by Reissman (2008).

Results

Findings/Discussions:
(a) Participants experienced an uncertainty in terms of their role transformation following the care-recipient’s diagnosis. (b) Participants experienced a moral distress due to their fear of the loss of care-recipient’s autonomy (c) Participants also experienced a moral distress due to a feeling of inadequacy in performing their caregiving duty.

Conclusion:
Caregivers experience a complete role transformation early in the diagnosis. Early interventions are therefore required to support their understanding of this new role. Periodic interventions are also needed to ensure understanding and coping within the role develop with the progressive decline of the person receiving care.

Key references

This work has been developed as part of an ongoing thesis by Charles James titled: ‘Moral Distress in Moderate to Advanced Dementia Care: An Exploration of Informal Caregivers’ Experience of Home-Based Care Provision at End of Life,’ and supervised in the Faculty of Health and Medicine by Catherine Walshe and Caroline Swarbrick. For more information, please email: c.james3@lancaster.ac.uk.