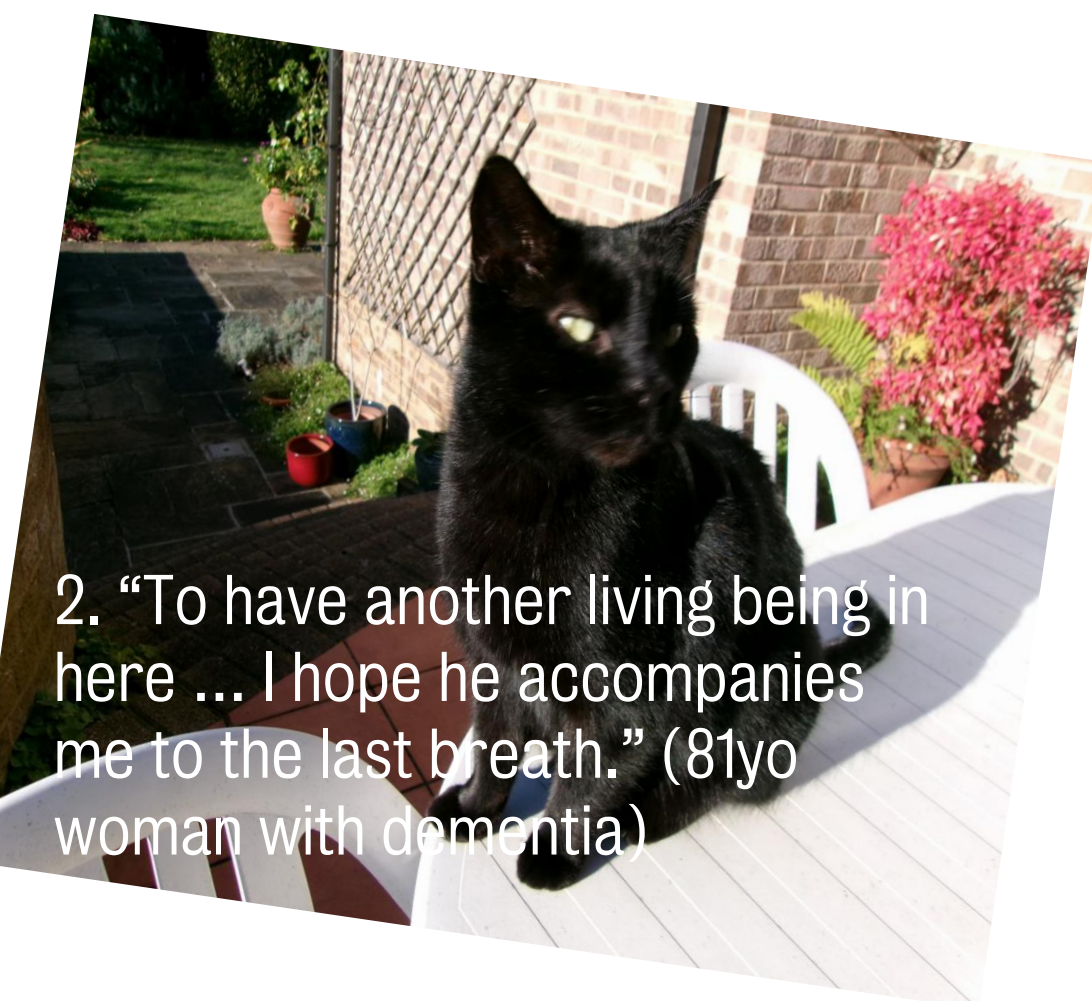


“Okay, that's my life story, goodbye” : a photo-elicitation study exploring what provides meaning when living and dying with dementia

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Our findings provide an **assets-focussed** understanding of how people with dementia may face approaching the end of their lives. Whilst **cognitive and social function loss are inevitable** as the disease progresses, supporting **selfhood and a sense of connection beyond oneself** may facilitate meaning, including **meaningful dying**.



2. “To have another living being in here ... I hope he accompanies me to the last breath.” (81yo woman with dementia)

1. Introduction

Dementia is the leading cause of death in England and Wales¹. However, the evidence-base to guide care for people with dementia approaching the **end of life** remains limited and the views of people with dementia themselves are underrepresented^{2,3}. This study aimed **to explore what is meaningful when facing the end of life from the perspective of people with dementia**.

2. Methods

Photo-elicitation methods were used to guide unstructured, face-to-face interviews⁴. Participants took photographs over a 12week period, which were then used as prompts for **qualitative interviews**. Interviews were analysed through a **hermeneutic phenomenological approach**⁵.

Use of participant-generated photographs was chosen in discussion with **Patient and Public Involvement (PPI)** members to facilitate expression of things that may otherwise be difficult to find words for, and act as an aide-memoire to support engagement.

People with dementia aged over 65 were recruited from Greater London via **purposive sampling** through community and charitable networks. A sample size of 10-15 was anticipated to provide **sufficient information power** to meet the study aims, whilst remaining feasible in the context of the intense analytical approach⁶.

3. Results

The experiences of **ten people** with early dementia were explored in depth. They shared similar sociodemographic contexts, being predominantly white (n=10) and female (n= 8). Half had achieved postgraduate education (n=5).

Analysis generated five **themes**: “1. **A familiar and safe space**’, ‘2. **Belonging through human & non-human relationships**’, ‘3. **Embodied touch and supporting the body**’, ‘4. **Telling the story to make sense of lived time**’, and ‘5. **A sense of connection beyond oneself**’.

When faced with the challenges their illness produces, participants found support in surrounding themselves with familiar objects and relationships that **connected them to their narrative history**.

In addition to **reinforcing selfhood**, meaning was found in recognising **connections beyond their selves**: engaging with nature or faith practices as means to contribute to those they would leave behind. The natural world in particular was described as a place to find feelings of peace and joy as well as reflect upon what **legacy** would be left when they were gone.

4. Conclusions

Meaningful dying in dementia is possible through supporting the personal story and recognising contribution beyond oneself.

5. “the trees just give me a feeling of peace. Real nature, oak trees and just gives you peace and yes, a feeling of joy even” (81yo woman with dementia)



1. “It's feeling safe, and because I feel safe, I feel happy” (80yo woman with dementia)

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