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“It’s not just about the patient, it’s the families too”: End of life care in the home environment

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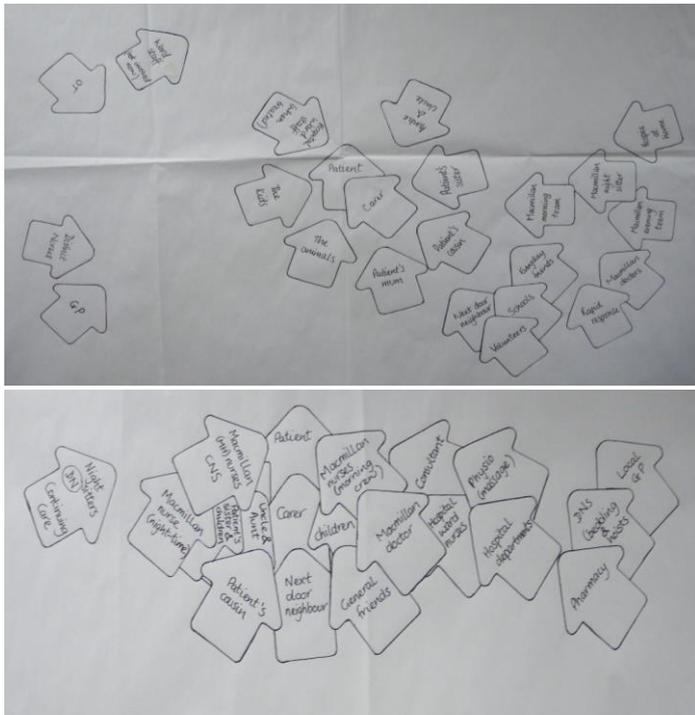
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Most people when asked say they would prefer to die at home. However, ‘**Death in Usual Place of Residence**’ (DiUPR) does not give any real insight into the quality of care received. Additionally, DiUPR involves **other family members** resident in the home environment, and their needs, preferences and experiences also need consideration.

The aim of this work was to explore the **experiences of patients and informal caregivers receiving at-home care** from a specialist palliative care service. We undertook interviews with 11 patients and 10 family informal caregivers. Interviews were analysed thematically.

We used the **Pictor technique**¹, a novel interview tool to sensitively explore networks of support and experiences of palliative care with professionals, patients and carers. Interviewees are asked to create a ‘Pictor chart’ using a large sheet of paper and arrow shaped Post It notes detailing all those involved in a care situation. The charts are then used to help participants reflect on their experiences with the interviewer.

Examples of patient (top) and carer (below) Pictor charts:



Interview extracts:

“Some days I just feel as though I want to get in the car and go, drive til the petrol runs out, doesn’t matter where I drive to, as long as I’m away from it all, let someone else deal with it, you know”

“When it was all first started, I felt I was being pulled from pillar to post by everybody, I didn’t feel anybody was in charge of my treatment. Because I had him doing one thing, the doctor doing something else, I had the district nurse doing – I had lots of care, but too much...and I just wanted somebody if you like to co-ordinate the whole thing. And I think [this service] sort of more or less filled that”

“My wife trusts her too and I think that’s important because if anything did decide to go wrong I would like to feel like she had got somebody that she knew quite well and that she could talk to and if the worst came to the worst, you know, she’d be there afterwards as well”

Caring for a loved one at home was acknowledged as draining, but participants were effusive about the **excellent at-home professional support** they received from the specialist service. The care provided evidently **recognised the needs of both patients and their families**. **Effective co-ordination of care**, including liaison with other services was especially appreciated.

Pictor is a useful tool to obtain detailed insight into individual experiences of end of life care. Care co-ordination emerged as a key concern for patients and their families. It is vital that there are **sufficient, well-resourced specialist palliative care services available in the community** to support both patients and their families at the end of life.

References:

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2. Noble, B., King, N., Woolmore, A., Hughes, P., Winslow, M., Melvin, J., Brooks, J., Bravington, A., Ingleton, C. and Bath, P. (2014). Can comprehensive specialised end-of-life care be provided at home? Lessons from a study of an innovative consultant-led community service in the UK. *European Journal of Cancer Care*, pp. 253-266.