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Undertaking qualitative research into end of life care in the home environment

Jo Brooks, Alison Bravington, Beth Hardy,
Jane Melvin and Nigel King



Background

- 75% of people say they would prefer to die at home (Department of Health, 2013)
- Number of people dying at home is increasing (42% in 2011), but over half of deaths still occur in hospitals (Department of Health, 2013)
- Too many people are not getting high quality care at the end of their life (ONS, 2014; Choice in EoLC Programme Board, 2015)



What is a 'good death'?

Being without pain

Being in a familiar place

Having significant others involved in care and supported

Being with close family or friends

Being treated with respect

Having access to the right services at the right time

Having support for physical, emotional, social and spiritual needs

Receiving high quality care from good staff

Having involvement in and control over care decisions

Issues for qualitative researchers doing research into end of life care

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- Challenges investigating patient experiences
- Challenges investigating significant other experiences
- Complex nature of care (Queens Nursing Institute, 2011)

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Our solution: The Pictor technique (King et al, 2013)

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- Visual research method that involves the creation of a chart that forms the basis of research interview
- Encourages participant to reflect on, and communicate their experiences with the researcher

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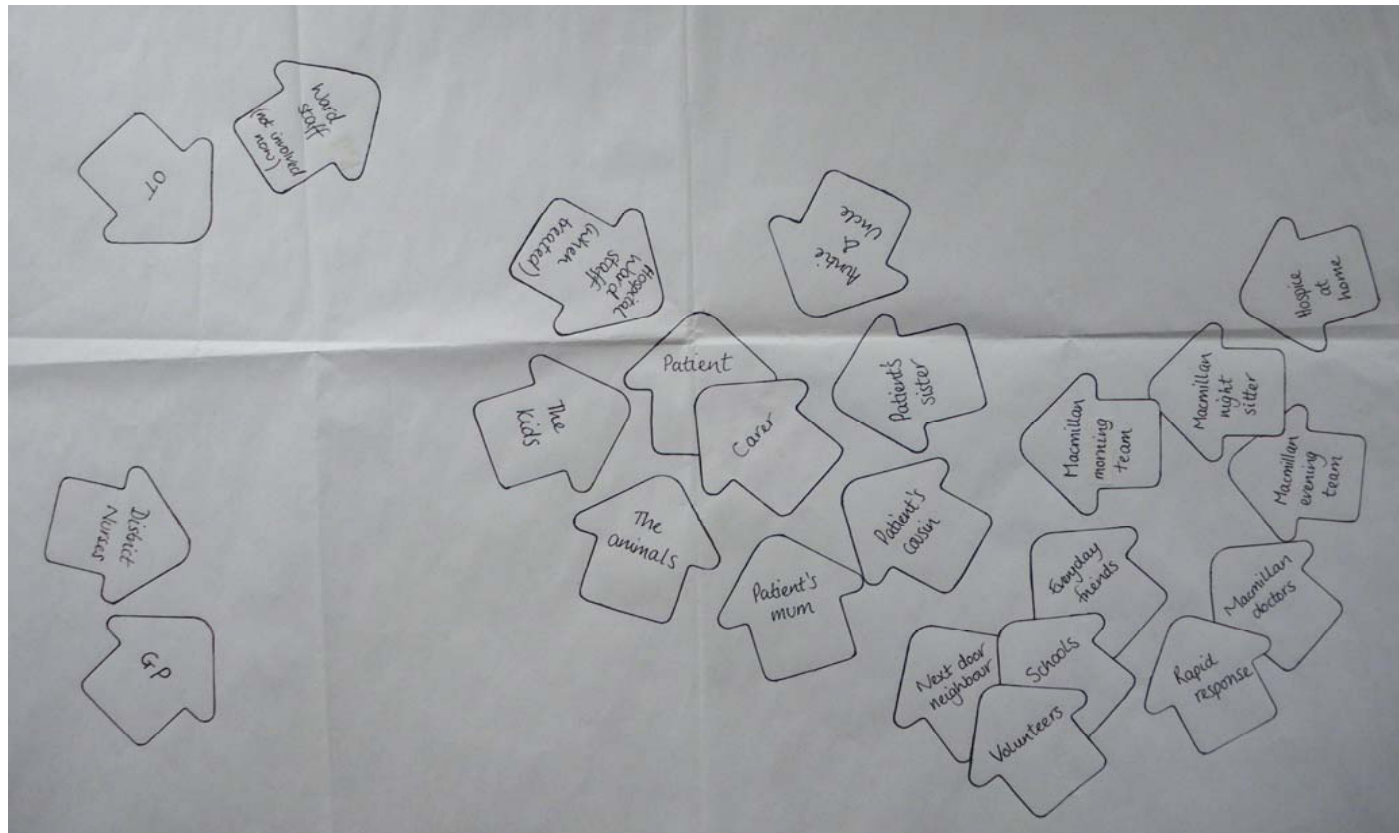
Our study

- Part of a larger research project evaluating a specialist service providing home-based care for patients at the end of life
- Participants: (1) 30 staff and volunteers from the service; (2) **21 patients and carers receiving treatment and/ or care and support from the service**; (3) 18 health and social care professionals involved in working with the service
- Individual interviews incorporating Pictor conducted with all participants



Example of a Pictor chart - patient

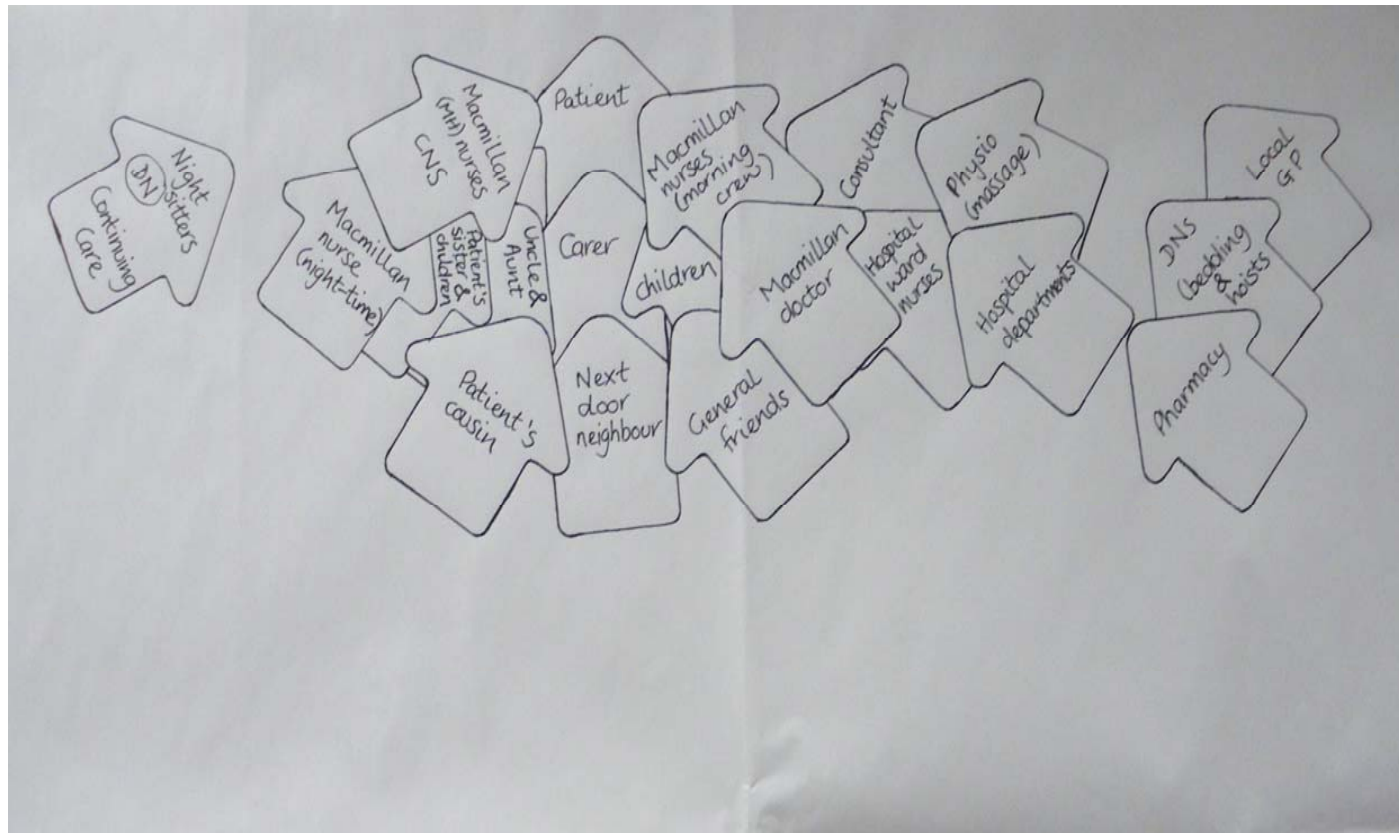
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Example of a Pictor chart - carer



Data Analysis

- We used **Template Analysis** (e.g. Brooks et al, 2015) to analyse our data
- Advantages:
 - Able to handle our (large) data set
 - An appropriate fit for our choice of approach (drawing on constructivist tradition)
 - Allowed analysis to proceed in parallel with data collection
 - Facilitated team analysis
 - Allowed us to develop a useful **integrative theme**



(Simplified) final template

1. How does the Service work with external services?

- 1.1 Policies, procedures and documentation
- 1.2 Understanding and negotiating who does what
- 1.3 Dealing with power and hierarchy

2. How does the Service work with patients and carers?

- 2.1 Genuinely holistic services provided for patients and carers
- 2.2 Finding ways in
- 2.3 Building up relationships
- 2.4 Patient/Carer awareness and utilisation of services available

3. Future directions

A.1 Integrative theme – what makes the Service special?

- A.1.1 Complex interventions
- A.1.2 In-house consultant operating in the community
- A.1.3 Service team dynamic
- A.1.4 Filling service gaps
- A.1.5 Prevents admission to hospital
- A.1.6 Reliance on volunteers
- A.1.7 Getting in early
- A.1.8 The Service Centre/clinic setting



Findings

- Caring for a loved one at home acknowledged as draining...

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

- ...but participants were effusive about the excellent at-home professional support they were receiving

[The service] has been outstanding... it's been wonderful to have them, it really has ... they go out of their way to try to do more than they're specifically here to do

Medicine is worried about the tumour, that's what they're interested in... [the service staff member] comes into it because she looks after our sort of total being



Findings cont.

- Genuinely holistic care evidently recognised needs of both patients and carers
- Effective co-ordination of care especially appreciated

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

Conclusions

- Need for **sufficient well-resourced palliative care services available in community** to support patients and their families at end of life
- **Care co-ordination** emerged as a key concern
- Recent independent report emphasises need for **care co-ordinators** and importance of **care in community settings** and suggests such care should be available 24/7 from 2020 [Choice in End of Life Care Programme Board, 2015]
- **Pictor** is a useful means for qualitative researchers to explore experiences from perspective of patients and family members, enabling detailed insight into individual experiences of end of life care (Noble et al, 2014; Hardy et al, 2014)



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