Receiving care in the last year of life: findings from research into the lived experience of patients and carers.

Beth Hardy
Beth.hardy@nottingham.ac.uk

Acknowledgements

Inspiring tomorrow's professionals

University of HUDDERSFIELD

Professor Nigel King, Dr Alison Rodriguez, Jan Firth

WE ARE MACMILLAN. CANCER SUPPORT

Macmillan Palliative Care Collaborative

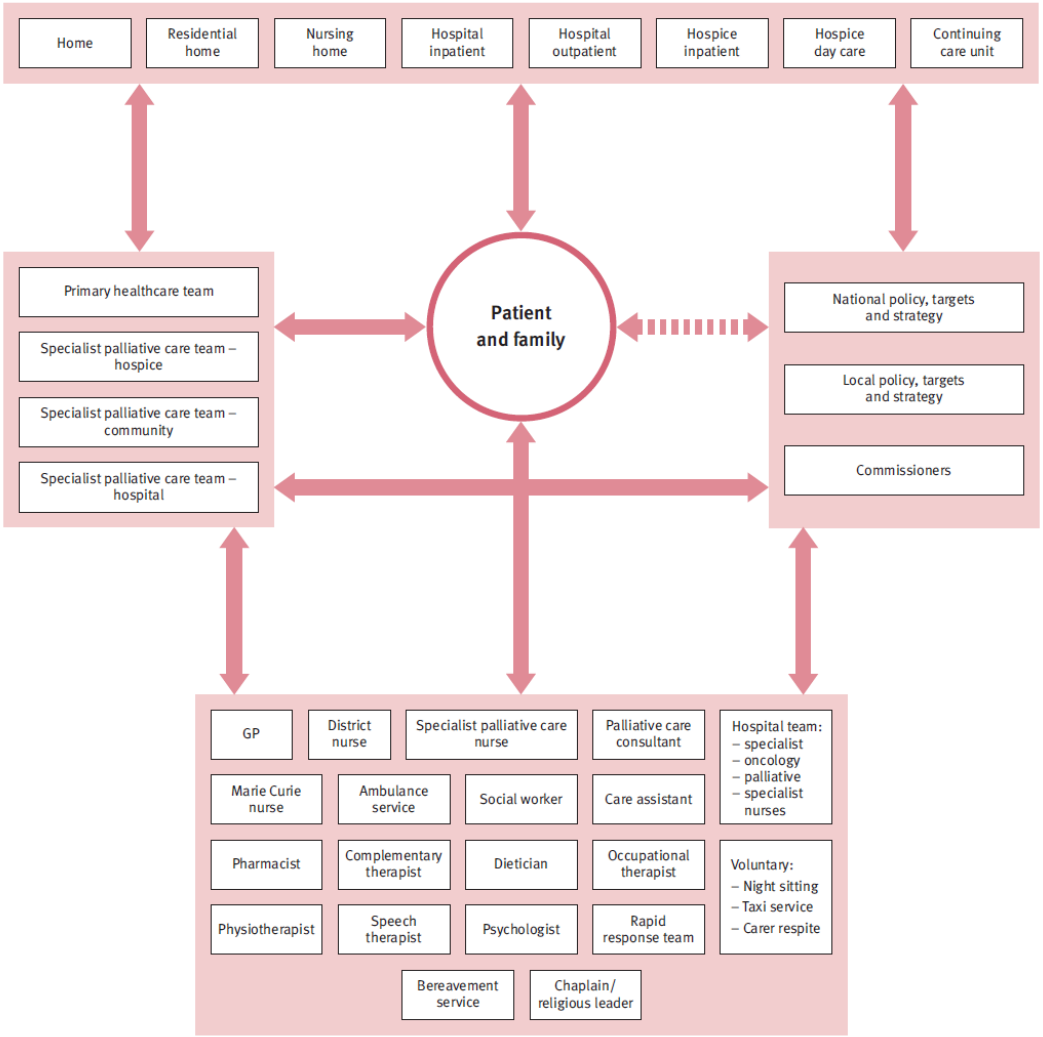
Research is….

‘Always a project of someone: a real person, who, in the context of particular individual, social and historical life circumstances, sets out to make sense of a certain aspect of human existence’ Van Manen (1990).

Background to the study

- Most of the last year of life spent in the community setting
- Increasingly complex interventions provided at home
- Aging population
- Change in disease management models of chronic disease = development of new community nursing roles and community services

1 PROVIDING PALLIATIVE CARE: A COMPLEX 'WHOLE SYSTEM'



Burt et al, 2005

Collaboration and the MDT

- The importance of collaborative working is recognised across policy, practice and education

- Challenges to this aspiration
  - Requires time to develop relationships, trust and respect (Downing 2012)
  - Care providers may not be co-located, may have different documentation systems, employed by different organisations and working towards different agendas (Victor 2000)
  - Poor understanding of others roles (McDonald and McCallin 2011)
  - Fears over role erosion from newly developed services, and conflicting views as to who should have a central role in care provision (king et al 2010).

To explore the lived experience of people affected by advanced disease, in relation to their contacts with multiple services.

Interpretive phenomenology

- **Phenomenology helps us to understand other's lived experience of the world.**
- **Phenomenological research exposes ordinary and everyday aspects of health care, and encourages the challenging of assumption.**
- **Phenomenological research methods can be flexible to the specific research question and population.**
- **Phenomenological research processes impact upon researchers themselves, having particular benefits for researchers who also work within clinical practice.**

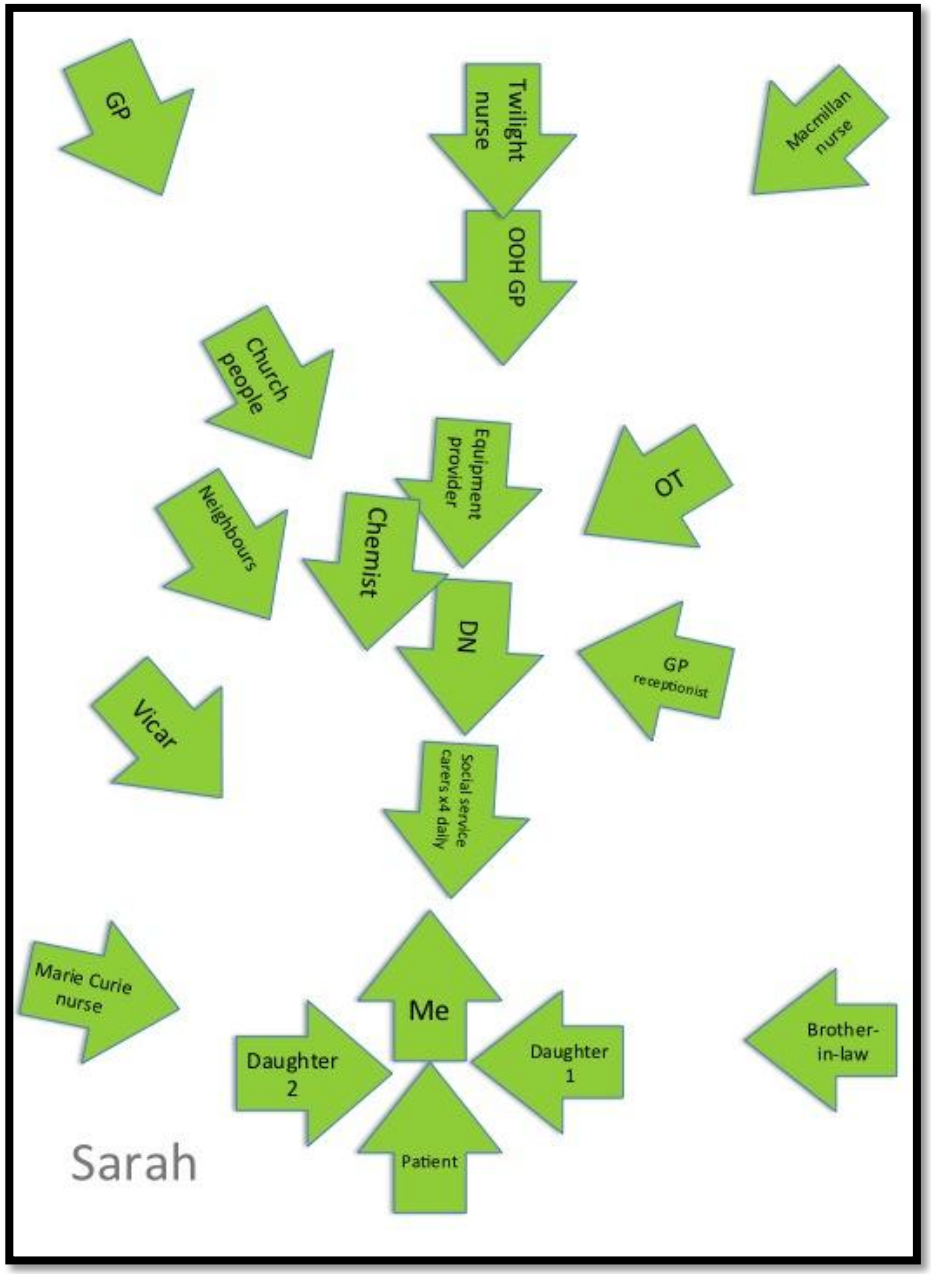
A anticipated data collection problem

People do not always know who it is that is delivering their care

(Queens Nursing Institute, 2011).

Pictor

- Visual research method based on the principles of PCP and Interpretive phenomenology
- Technique involves the creation of a chart that forms the basis of the research interview
- Encourages the participant to reflect on, and communicate their experiences with the researcher.


GP
Twilight nurse
Macmillan nurse
OOH GP
Church people
Equipment provider
OT
Neighbours
Chemist
DN
GP receptionist
Vicar
Social service Carers x4 daily
Marie Curie nurse
Me
Brother-in-law
Daughter 2
Daughter 1
Patient
Sarah

Method

- Van Manen
- One healthcare trust
- Patients with a high likelihood of dying with the next 12 months –assessment using the PIG
- Interviews with 12 patients and 8 spouse carers
  - Cancer
  - COPD
  - Heart failure
  - Parkinson's Disease
- Pictor Technique in all interviews
- Data analysed using phenomenological techniques and Template Analysis.
- Writing as method in interpretation

Findings

Integrative theme: the interconnectedness of patient and carer experiences.

1. Recognising illness: recognising services

1.1 They do things to me: we do things together
1.2 Helping me face my illness: the comforting presence of services
1.2.1 Previous invisibility of services
1.2 Services reducing the isolation of illness
1.2.1 Being different
1.2.2 Being understood
1.2.3 Acceptance of death and dying

2. A partner who is ill: being a spouse, being a carer

2.1 The patient focus
2.1.1 *'There's no support for me'...*
2.1.2 *'I don't want to cry in front of him':* Partners presence restricting the spousal-carer's opportunity for discussion with health services
2.2 Declining service involvement
2.2.1 *'And of course I said I am fine'*
2.3 *'My strength'*: support from friends and family
2.4 Always watching: a unique insight
2.4.1 Specialist knowledge: contribution to, and rejection from the care team

3. My care team: using a team that works for me

3.1 Coordinating and managing the team
3.2 Significant health service relationships
3.2.1 Individuals, not role
3.2.2*'like'* a friendship
3.2.3 Knowing them, knowing me
3.2.4 Listening to me
3.2.5 Not solving the unsolvable
3.3 *'My Doctor':* GP involvement
3.3.1 Desire for holistic and supportive involvement
3.3.2 Secondary to other services
3.3.3 In acute illness

3. My care team: using a team that works for me
    - 3.1 Daily managing
    - 3.2 Significant health service relationships
        - 3.2.1 Individuals, not role
        - 3.2.2 *'like'* a friendship
        - 3.2.3 Knowing them, knowing me
        - 3.2.4 Listening to me
        - 3.2.5 Not solving the unsolvable
    - 3.3 *'My Doctor':* GP involvement
        - 3.3.1 Desire for holistic and supportive involvement
        - 3.3.2 Secondary to other services
        - 3.3.3 In acute illness

Significant health care relationships

- Relationship, not role…
- ‘Like’ a friendship
- Knowing them, knowing me…
- Listening
- Not solving the unsolvable
  - One or two individuals were often described as being particularly valuable
  - Relationships varied in length of time and the role the person was in
  - Commonalties included where the care provider recognised them as a person and recognised their personal experience of illness.
  - The ‘authentic’ relationship

And I think that's the main thing, when they just listen to you. You know, when they're not butting in and saying well you know, *'take him to hospital, take him to...'*- he doesn't want to go to hospital, he's frightened he's not going to come out. *'Well there nothing I can do'*, but she listens to me (GP work colleague). She lets me moan on about it, *'well there I am again doctor, a barrel of laughs as usual'* (laughs), she just, (laughs) she just laughs with me.

Sue

Daily Managing

It is perhaps not surprising that some people take on a management role in their own care, as people who have spent a lifetime managing their own lives, coordinating families, managing budgets and resources do not suddenly lose these skills because disease has entered their lives (Kellehear, 2007).

- Dyadic - Patient and spouse carer
- 'front line' managing between care contacts
- active information sharing and co-ordinating role

Everyday choices

- Many people involved in care:
  - who to ring when there is a issue?
  - Assessing significance of problem and where questions should be directed
  - Whether to follow advised course of action

- Choices based on a number of variables:
  - previous experience of a service, personal knowledge and preference, advice of peer networks, confidence in clinical care, availability, personal relationships, a sense of being known.

- ‘correct’ services bypassed

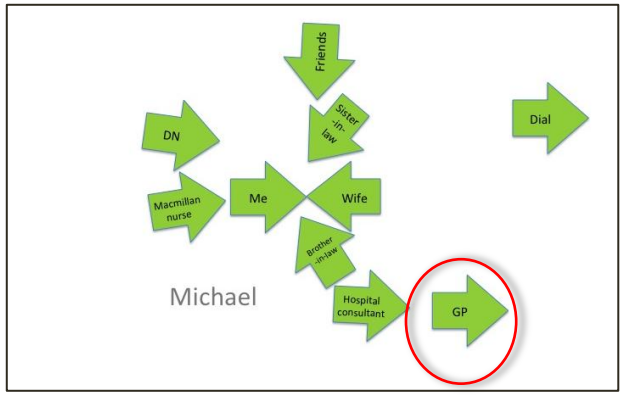
I’m supposed to ring her (practice nurse) and it’s supposed, they’re supposed to all be involved but I find it easier ringing (respiratory nurse specialist)… oh to be honest, I don’t like the practice nurse. P7

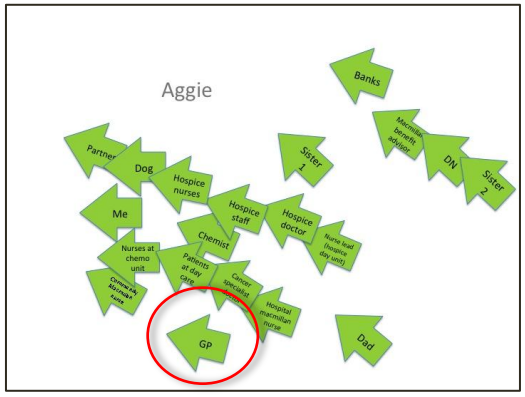
Strategies for daily managing

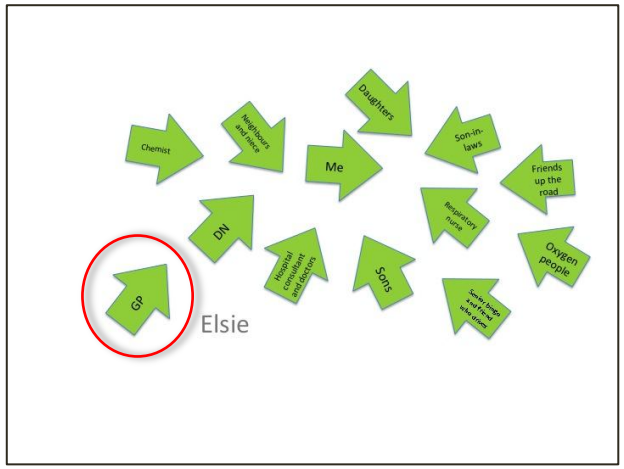
- Practical strategies
- Experientially learning methods of obtaining care and adapting strategies accordingly
- Confidence in these strategies obtaining the required response significant factor in people feeling like they could continue to manage the care situation and gave them confidence in the their ability to cope with illness.
- When strategies fail the situation can feel out of control

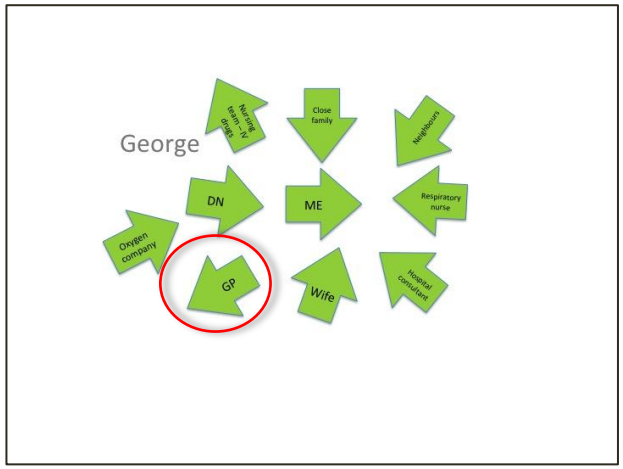
But that was on the Friday, on the Saturday I rang the emergency doctors because of course all of the surgeries are closed, and they sent a nurse out and gave him an injection, which didn't' do any good, and I rang again. And all Saturday night I must have spoken to 13 or 14 different people on the phone. And at a certain point you get away from the emergency doctors to NHS direct. Horrendous, Absolutely horrendous.

‘My Doctor’


Friends
Sister in-law
DN
Dial
Macmillan nurse
Me
Wife
Brother in-law
Michael
Hospital consultant
GP


Aggie
Banks
Partner
Dog
Hospice nurses
Sister 1
DN
Sister 2
Me
Hospice staff
Hospice doctor
Chemist
GP
Dad


Daughters
Chemist
Me
Son-in-laws
Friends up the road
DN
Oxygen people
Sons
GP
Elsie


George
Close family
Neighbours
DN
ME
Respiratory nurse
Oxygen company
GP
Wife
Hospital consultant

‘Caring for people nearing the end of their lives is part of the core business of General Practice’

Thomas, 2009.

- GP described as ‘My Doctor’.
- Anticipation that the GP would have a central role in care
- A desire for regular involvement – even where no medical need identified, or needs being met by others.
- Lack of regular involvement sometimes interpreted as lack of respect and care.
- Desire for recognition from their GP, for their doctor to hear their story and acknowledge their experience.

BH: Now, you've not included the GP on here?

Sarah: Well I haven't seen him since Paul was ill. Right, not seen the doctor at all. I mean I'll put him on, but right on the periphery. Yea. That doesn't mean to say he wouldn't come if I asked him. But, I think that I thought he might just come you know, and call in just to see how things were going. But I do know that I would get one if I asked for one.

it wouldn't hurt just once a month for somebody *(the GP)* to do a visit. I think you'd feel slightly more reassured.

So what…..?

- Relationships matter
  - The ‘authentic’ relationship
  - Skills required to enable this
- Each persons ‘health care team’ is different
  - Supporting people to understand and navigate this team
  - Communication of role
  - Appropriate utilisation of team
    - Further research needed
- Practice needs to attend to everyday decision making


ANY
QUESTIONS
?

References

- Burt, J., Shipman, C., Addington-Hall, J. & White, P. (2005) *Palliative Care. Perspectives on caring for dying people in London*. London: Kings Fund Publications.
- Downing, J. (2012) Collaboration is palliative care: crucial but poorly defined. *The International Journal of Palliative Nursing*, 18, (6) p. 263.
- DH (2008) *End of Life Care Strategy*. London: DH Publications.
- McDonald, C. & McCallin, A. (2011) Professional collaboration in palliative nursing: what is the patient-family role. *International Journal of Palliative Nursing*, 16, 6, pp. 285-288.
- King, N., Melvin, J., Ashby, J. & Firth, J. (2010) Community palliative care: role perception. *British Journal of Community Nursing*, 15, (2) pp. 91-98.
- NEoLCP (2011) *Route to Success: The key contribution of nursing to end of life care* (online). Available at: http://www.endoflifecareforadults.nhs.uk/assets/downloads/RtS_Nurses___Revised_Web_20110097.pdf
- QNI (2011) *Nursing People in the Home. The issues, the stories, the actions.* London: The Queen's Nursing Institute.
- Thomas, K. (2009) RCGP End of Life Care Strategy (online). Available at: http://www.rcgp.org.uk/pdf/CIRC_RCGP%20End%20of%20Life%20Care%20Strategy%20FINAL%20Jan09%20(Prof%20Keri%20Thomas).pdf .
- Van Manen, M. (1990) *Researching Lived Experience. Human Science for an action sensitive pedagogy.* New York: State University of New York Press.
- Victor, C (2000) Health Policy and services for dying people and their carers. *In:* Dickenson, D., Johnson, M. & Samson Katz, J. eds. *Death, Dying and Bereavement*. London: The Open University in association with Sage Publications, pp. 44-53.