'What Matters' To Older Carers

Prof Alisoun Milne
Professor of Social Gerontology & Social Work, School of Social Policy, Sociology & Social Research, University of Kent
Why focus on ‘what matters’?

- Older carers have a distinctive profile
- Tend to ‘slip off’ the policy, practice & research radar
- A population(s) recognised to a greater degree now but there is much still to do
- One of the key tasks relates to how we understand the needs, perspectives & worlds of older carers
- How we conceptualise ‘what matters’ is a pivotal issue: if we don’t understand this how can we develop appropriate & sustainable responses
Lloyd (2006) many ‘carers’ do not recognise, or are reluctant to define, themselves as carers.

Concerns re it subsumes other identities such as that of partner, parent, son/daughter.

Also concerned to protect the cared for person who may feel that they do not ‘need care’ or are a ‘burden’.

Carers may minimise carer related work resisting ‘framing’ it as ‘caring’: prevents identity disruption & resist threats to existing relationship.

Actively hide the role of carer; normal family responsibility.

Carers may also resist recognising the impact of caring on themselves: less likely to ask for support.

For spouse carers the marital contract, a shared life-course, mutuality and interdependence are evidenced as underpinning commitment to providing care (Ray & Phillips, 2012).
Many older people don’t see themselves as carers.

“It was only when we made contact with the Carers Centre, and we explained a few things that the assistant manager [said] you are all carers ...

Many people just see themselves as a wife or husband... doing caring as part of their normal role”

Knowles et al, 2015
Carers' Work

Growing evidence that older carers are engaged in three types of care work: *illness-specific work, everyday work & emotional work*

### Emotional Work

Emotional work is a prominent feature of older carer’s work. It tends to be complex, opaque, nuanced & subtle and includes:

- Diffusing worry and anxiety; presenting a ‘life as normal’ narrative
- Managing biographical aspects of ‘care’ such as bolstering the cared for person’s identity and roles, independence and self-management
- Resisting threats to existing relationship: protecting the dyad - the ‘we-ness’ dimension (Hyden & Nilsson, 2013)

### Illness-Specific & Everyday Work

- **Illness-specific work:** such as managing medications, helping to relieve or manage symptoms
- **Everyday work:** personal care such as bathing and toileting, physical care such as dressing and moving and handling
The emphasis (by the older carers) was on supporting the *emotional work*, or helping with the illness specific work in a subtle, even disguised, way to avoid threatening the independence of the cared for person.

“*I’m like a security blanket... My husband is able to care for himself so long as I am available in the background...*”


Re-Framing Care:

Care Embedded in Relationship

- Dementia care literature emphasises ‘the We-ness dimension’ (Hyden & Nilsson, 2013)
- Coming to terms with dementia & managing change & challenge is a dyadic project
- Couplehood is maintained
- Emphasis on we-ness also implies a care approach that takes the couple as the ‘starting point’ rather than ‘the person with dementia’ and ‘the carer’ separately
- Care is embedded in lifelong relationship: part of the shared lifecourse (Ray & Phillips, 2012)
Balancing Care and Protection

- Tensions between care and protection in relation to caring for people with dementia are increasingly recognised

- Askham et al (2007) identified three dimensions to the ‘balancing’ act:
  - Custodial care
  - An intimate relationship &
  - Home life

‘Homes are not total institutions and people with dementia are not inmates. But living at home with a person with dementia brings the challenge of how to preserve home life and an intimate relationship alongside providing care and custody…. Living with a person with dementia is a complex balancing act that is difficult to sustain. It is in constant danger of slipping towards the practices and life of a total institution’ (p21)
What Matters in Practice

- Good quality assessment & personalised packages of care are much more likely in contexts where the older person’s & their carer’s perspectives are responded to:
  - “…where due weight is not given to the older person - and their carer’s - perspective in assessments the risk of inappropriate intervention is considerably greater” (Richards, 2000)

- Evidence that assessing the needs of the care/carer dyad offers basis for sustainable care (Gridley et al., 2012)

- Lack of ‘fit’ between older carers’ needs & service models = focus on instrumental care tasks

- Conceptual frame fails to take account of the emotional work related to caring; nor easily accommodate a duty to promote carer well being

- Services underpinned by assumption that carers want to - and should - continue to care
The Process of Care

- Service system fails to recognise dynamic & nuanced nature of caregiving

- Caring ‘evolves over time’ & changes during the course of the care ‘journey’ (Bowlby et al., 2010)

- Older carers may present a positive picture & only disclose difficulties once a trust relationship is established (McGarry & Arthur, 2001; Moriarty & Manthorpe, 2016)

- Older carers value a trust relationship with a knowledgeable professional who will:
  - Help navigate the ‘care system’: many find it complex & confusing
  - Offer tailored advice re services, the law, planning for the future
  - Recognise the carer’s own rights and needs
  - Recognise reciprocity & relational issues
  - Acknowledge reluctance to identify as a carer
  - Acknowledge the carer’s own account of care, concerns & fears
  - Engage with the challenges of caring: loss, abuse, sadness, anger
What about Research?

- ‘What works’ is a question generated from within a specific research paradigm: the ‘gatherers & evaluators’ (Henwood, Larkin & Milne, 2017; Milne & Larkin, 2015)
- This paradigm is driven by policy concerns & generates a specific kind of ‘evidence’
- This model is at odds with the concerns & perspectives of older carers
- For research to be meaningful to carers & inform services & practice it needs to face towards:
  - The more complex realities of people’s real lives
  - Capture the nuanced emotional work that carers perform
  - Capture their lived experiences
  - Speak to the care relationship
Future: what needs to be done?

Health & social care professionals proactively recognise and validate older carers.

Care is embedded in dyadic relationship, recognising wellness & couple identity.

Recognise work with older carers as complex & skilled, time rich & requiring a trust relationship as basis of good practice.

Research needs to reframe ‘what works’ to take greater account of ‘what matters’.

Recognise & value the more collaborative & subtle nature of emotional care work.
References


Moriarty, J and Manthorpe, J (2016) *The effectiveness of social work with adults*, SCWRU