Knowledge Generation about Care-giving in the UK: Critical Review of Research Paradigms

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Care & Carers: Research Paradigms

- Although carers are the focus of considerable research limited attention has been paid to the nature of the evidence base & its links to the generation of knowledge
- Critical review of research: how do we generate knowledge about care & carers
- Implications for understanding of, & support for, carers
- Review draws on literature from 1995-2014: Carers Act 1995 (Milne & Larkin, 2015)
- Arena is dominated by two research paradigms:
 - 'Gathering and Evaluating'
 - 'Conceptualising and Theorising'

'Gathering & Evaluating'

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'Conceptualising & Theorising'

'Gathering & Evaluating'

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Paradigm 1: Gathering & Evaluating

- This paradigm is closely aligned to the dominant discourse about caring in the UK
- Primarily focuses on profiling the number, nature & extent of caregiving
- Provides evidence about the impact of caring on carers health & wellbeing
- Evaluates the effectiveness of carerrelated policy & services

'Conceptualising & Theorising'

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Paradigm 2: Conceptualising & Theorising

- Second paradigm: explores conceptual, experiential & theoretical nature of caring
- Explores the situated context of caring (relational, life course, structured) & carers' lived experiences
- Developed conceptual models relating to caring (carers as unpaid members of workforce)
 'Theoretical frameworks' - extended understanding of caring (eg Tronto's 'ethic of care', Kittay, Bowlby)

Generating Knowledge about Carers & Caring: is research fit for purpose?

The growth in research about family care has:

- Raised the profile of carers in the public domain & ensured 'that caring is prioritised as a significant issue for policy & practice' (Barnes, 2006)
- Underpinned the development of a highly organised & politically active carers movement, &
- Extended understanding about care and caring

BUT ...

- The majority of carer related research belongs to one of two distinctive & separate paradigms
- An issue epistemologically but also there is a reinforcing link between the type of research & the nature of knowledge generated

'Gathering & Evaluating'

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'Conceptualising & Theorising'

Gathering & Evaluating: Reflecting on the Evidence Base - Strengths

- Primary foci of work is twofold:
 - Enumerating carers, what they do, & with what effect;
 - Assessment of the impact & effectiveness of policy & services



- Helped to foreground caring as an issue inside government & nationally e.g. Census includes a question on carers
- Much of the work is positivistic, quantitative & methodologically rigorous
- Research findings are often accessible, 'useful'& 'trusted'
- Work strongly influences policy makers & nature of service investment; funded by UK Department of Health & health funders

Gathering & Evaluating:

Weaknesses

- Individual projects may be strong but as a whole the evidence base is fragmented & uneven
- Significant differences between the focus, size, methodology & nature of projects
- Differences weaken the additive capacity of the evidence base: duplication is not uncommon
- Studies tend to focus on 'visible' carers
- The impact of projects is limited eg assessments of need
- Research is conceptually narrow & under theorised:
 - Dichotomy between carer and cared for
 - Snapshot' nature of the work: care = static not dynamic
 - Underpinned by a stress/burden model of caregiving
 - Role of services is to relieve carers & extend their capacity to care

Conceptualising & Theorising: Reflecting on the Evidence Base - Strengths

- Work adopts a wide lens of analysis
- Care & caring are viewed as embedded in ordinary relationships: not an 'exclusive activity'
- Underpinned by an understanding that care is multi-dimensional:
 - A way of conceptualising personal & social relations; a set of ethical & moral values, and a practice (Barnes, 2012)
 - Work challenges narrow conceptualisation of 'care' & 'carer' that dominates policy & services
 - Emphasises interdependency & the normalcy of caring
 - its importance 'in the everyday' (Bowden, 1997)
 - Highlights the complexity & embedded nature of care
 - Rooting research in the experiences of families
 - Capture emotional dimensions of care

Conceptualising & Theorising: Weaknesses

- Limited foothold in policy & service related discourse & in public perception of 'care' & 'carer'
- Focus of work is also unclear: defining who is the focus of changes linked to an ethic of care is a challenge
- Lack of capacity to speak to economic agenda
- Limited absorption into health & social care services
- Field asks for infusion of 'care thinking into political thinking' (Tronto, 2010)
- Aims profoundly at odds with a welfare system that defines fewer & fewer 'carers' as 'eligible' for support & expects more & more from families



Conclusion

- Research pivotal to generating knowledge & enhancing understanding about care & caring
- Two separate research paradigms with very different perspectives & approaches dominate the field



- Very limited capacity to pool methodological & intellectual resources or develop synergies
- Drawing on strengths from both paradigms & encouraging cross fertilisation could:
 - Facilitate the development of new knowledge
 - Meet the needs of citizens, families & carers more effectively, &
 - Develop new paradigms to address current & future care related challenges

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