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Understanding Family Care: Building on the past to inform the future

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by

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Life is like a ten-speed bicycle. Most of us have gears we never use.



Building on the past

- Carer movement (UK) is 50 years old this year
- Actively involved in carer research for 30 years
- Time to reflect on what we currently 'know', and how we 'understand' family care?
- 'Trying hard but could do better' (School Report 1964)
- 'Whilst there have been many positive developments, much remains to be done' (FCA 2012)
- (The) 'experiences of carers today show we still have far to go' (Carers UK 2015)
- What do we need to better understand to address future challenges?



Understanding family care: Any changes?

- Exponential growth of the 'carer' movement (Carers UK, FCA, Eurocarers, Carers Australia etc) and therefore far greater recognition of 'carers rights'
- 'The state of caring' (Carers UK), 'Caregiving in the US' (AARP), Census data: Demographics of care, Who does what, how often, for how long etc
- What carers want, and to an extent, when, (but often don't get): Carers Manifesto (Carers UK 2015); Income and Care, Health and Care, Employment and Training, Recognition, information and advice
- Are we 'Data rich but theory poor' ? (Bengston et al 1997)



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**You can't discuss something with someone
whose arguments are too narrow**



Understanding family care: The development of 'theory'

- Kahana, E. and Young, R (1990) Challenging the caregiving paradigm: challenges for the future
- Little account of diversity and complexity
- Unidimensional: burden too dominant,
- Unidirectional and asymmetrical: Negative effects on the carer, or positive effects on the 'cared for'
- Static: Failed to account for changes over time
- Relational, dynamic, interdependence, temporal
- Dyadic and triadic approaches



Are we still unidimensional? : What is this thing some call caregiving? (Gubrium 1995)

- Considerable progress, now far greater recognition of the multidimensional nature of caring
- BUT the dominant discourse is still focussed on burden and negative impact of caring
- Caring is still primarily talked about in instrumental terms, ADL, IADL, complex 'medical' tasks (AARP 2014)
- Calculate the value of caring only for those who provide ADL or IADL (Fienberg et al 2012)
- Colours how we think about the type of support needed, and who should get it. Limits our imagination, satisfactions, enrichment, resilience.



Temporality: Is our understanding still static?

- ‘The form, content and timing of interventions should depend to a considerable extent on where carers are in their careers, and involve an understanding of what has passed before, and what is likely to lie ahead.
(Aneshensel et al 1995)
- Several quite sophisticated temporal models of caring
- Far better understanding of the ‘transitional’ nature of much caring, 2.1 million ‘new’ carers each year (Carers UK 2014)
- Still need to understand more about the caring ‘journey’
(Newbronner et al 2013)



Crisis, what crisis?

- Most carers only come to the attention of the 'system' at a time of crisis (Carers UK 2014)
- Services are reactive, not proactive and preventive
- Often uncoordinated, unreliable and of poor quality (Carers UK 2014)
- 'Taking it on': often at a time of crisis, carers are unprepared, no choice, little assessment, no consideration of their skills, values and preferences (Bauer et al 2009, Lutz and Young 2010, Reinhard et al 2011, Feinberg et al 2012)
- We are still not 'timing it right' (Cameron and Gignac 2008)



Reaching the end and a new beginning

- Entry to care: At a time of crisis, little forward planning, rarely receive adequate help, relationships with providers competitive rather than collaborative
- Palliative and end of life care: recent growth area but still relatively little research, carers unprepared, lack skills, unsupported, potential for long-term negative effects
- Carers feel largely unprepared for a life after caring (Eurocarers 2009, FCA 2012)
- Services usually cease at such a time
- Need for early and meaningful dialogue and support

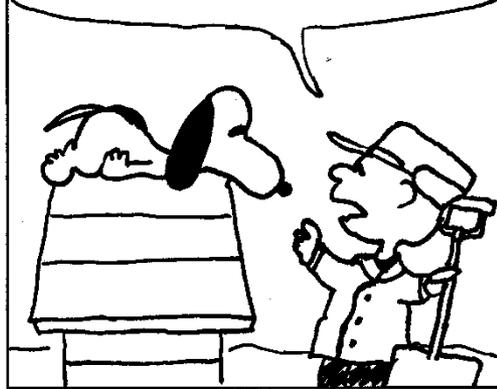


Is our understanding still asymmetrical?

- Considerable progress, now much more likely to explore the experiences both carer and the person they are supporting, the dynamics of care are better understood
- Most studies still dyadic, but family systems approaches now gaining far wider purchase, underpinned by ideas of 'co-construction'
- Still a limited understanding of the experiences of the person in receipt of support and their contribution
- Triadic relationships and interactions more of a focus, the discourse is of partnership and sharing of expertise between carers, people they support and service systems
- But reality lags behind, with a few exceptions eg COAT



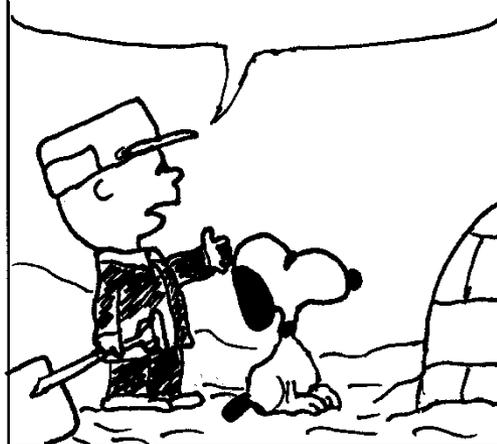
*Do you know what I'm going to build for you?
An igloo!*



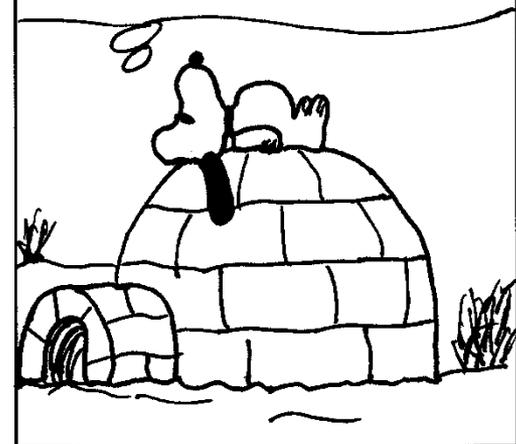
I think this will be just the thing for you to have during the cold winter months...



There you are ol' buddy... try it out!



I'm not quite sure that I see any advantage...





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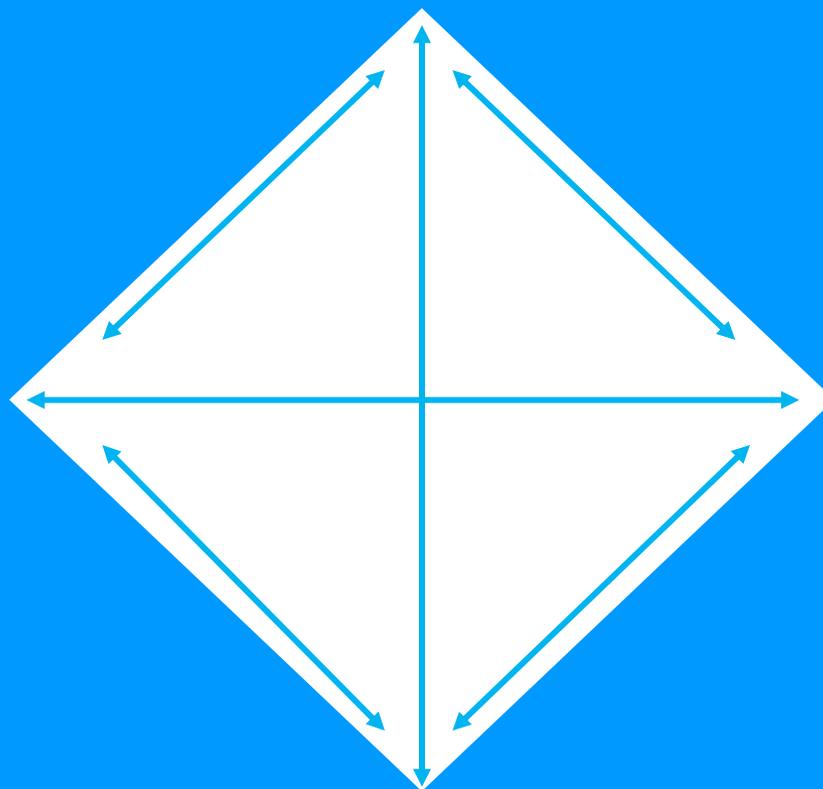
The Therapeutic Quadrangle

(Rolland 1988)

CARER

FAMILY

SUPPORT



CARED-FOR
PERSON

ILLNESS/DISABILITY



Ethical Challenges for the future

- **Choice** : Do carers have any **real** choice as to whether to enter or relinquish care?
Choice is one of the 10 guiding principles (Eurocarers 2009) but rarely achieved (FCA/AARP 2013)
- **What are we willing to pay for?** 64% of carers never access any support (Carers Trust 2012), carers experience considerable financial disadvantage (Carer UK 2015), 61% of agencies supporting carers have cut budgets, 53% increased workloads, 50% reduced staffing, direct care staff earn 50% less (FCA 2011)



Informing the future?

- ‘Good but could do better’?
- ‘What is this thing some call caregiving’?
- Still need to broaden the focus beyond the instrumental
- More attention to relational and dynamic models that capture complexity, from multiple perspectives, over time.
- Need to be more creative in designing support which ‘Accentuates the positive, eliminates the negative’.
- Solutions are more conceptual than methodological
- More effective ways of working in partnership
- Adopt an ‘epistemology of humility’ (Post 2001)



Looking to the future: Creating enriched environments of care

	Service Users	Family Carers	Staff	Students
Security				
Belonging				
Continuity				
Purpose				
Achievement				
Significance				

