Unpacking Carers’ Burden

Amaya Alvarez
Future Social Service Institute
RMIT University
Overview

1. What carer burden is and how it is assessed – and the evidence for what the sources of burden can and might be – broadly

2. Burden is a problem BUT how that problem is represented has huge repercussions for the way it is dealt with and for carers own recognition, rights and the quality of their lives

3. Using Carol Bacchis’ WPR (What’s the Problem Represented to be) will argue that Carer Burden is represented in three (sometimes overlapping sometimes contradictory) ways

4. Conclude with the point if we construct the problem outside the Carer Dyad and in the community and State - a range of different strategies and approaches are required.
WPR – what is the problem represented to be?

1. What’s ‘carer burden’ represented to be in a specific policy
2. What assumptions underpin this representation of ‘carer burden’?
3. How has this representation of the ‘carer burden’ come about?
4. What is left unproblematic in this problem representation? Where are the silences?
   Can ‘carer burden’ be thought about differently?
5. What effects are produced by this representation of ‘carer burden’?
6. How/where has this representation of ‘carer burden’ been produced, disseminated and defended? How has it been (or could it be) questioned, disrupted and replaced?

Carol Bacchi WPR (2012)
WPR - Carer Burden – The problem is represented as:

1. Either seen as something in the private sphere, contained within the home, and the care relationship negotiated there; (See for example Awad, G et al. (2008) *The Burden of Schizophrenia on caregiver: A review*)

2. or as a consequence of the lack of support and services for carers within the home or in the informal spaces of families and private households; (Carers NSW (2016) *Gives us A break: Evidence that Australian Carers still need respite*) —

WPR - focus

Much current research and effort in addressing ‘carer burden’ concentrates on:
1- managing carer stress and
2- trying to improve the conditions for carers in private households

not on how to the ‘hollowing out’ of State leaves carers with few choices and with increasingly complex and demanding work.
Dimensions of burden

1. Effective burden (measurable – to an extent)
   
   What carers do – activities/tasks
   
   • Physical support/care, support with tasks of everyday living, health management, medical oversight, bureaucratic interface,
   • and emotional support/care – coaching motivating, facilitating social engagement, managing distress, expressed emotion, encouraging them, carrying their stories, seeing them valuing them

2. Affective burden – how carers feel (subjective)
   
   Carer wellbeing, stress, relational dimensions – tiredness, hopelessness, anxiety, guilt, worry for the future, isolation (both social and emotional)

   Carer Burden is linked to the intensity and complexity of these dimensions of care
Carer Burden...

Both effective and affective care work have:

• Spatial – where care/support takes place – in home – in same home
• Temporal – how many hours and over how long, and how long envisaged - affective care can never end (worry anxiety about future)
• Relational – parent, child, adult child, partner/spouse, friend different history intensity and assumptions
• Socio-Economic – financial security, engagement with employment, the welfare state, superannuation savings, navigating fragmented systems etc

Dimensions..
## Assessing burden

### Quantitative burden measures (Vitaliano et al., 1991c)

<table>
<thead>
<tr>
<th>Authors</th>
<th>Burden measure</th>
<th>Domain</th>
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</thead>
<tbody>
<tr>
<td>Zarit et al (1980)</td>
<td>The Burden Inventory</td>
<td>✓</td>
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<tr>
<td>Greene et al (1982)</td>
<td>Behavior and Mood Disturbance Scale</td>
<td>✓</td>
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<tr>
<td>Robinson (1983)</td>
<td>Caregiver Strain Index</td>
<td>✓</td>
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<tr>
<td>Poulshock and Deimling (1984)</td>
<td>Poulshock and Deimling's Model</td>
<td>✓</td>
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<td>Montgomery et al (1985b)</td>
<td>Montgomery, Gonyea and Hooymans Inventories</td>
<td>✓</td>
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<td>Kinney and Stephens (1989)</td>
<td>Caregiver Hassles Scale</td>
<td>✓</td>
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<tr>
<td>Novak and Guest (1989b)</td>
<td>Caregiver Burden Inventory</td>
<td>✓</td>
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<tr>
<td>Vitaliano et al (1991a)</td>
<td>Screen for Caregiver Burden</td>
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Cared for as burden?  

Caregiver Burden Scale

Caregiver's name: ____________________________ Date: __________________

The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Nearly always</th>
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<tbody>
<tr>
<td>1. Do you feel that your relative asks for more help than he or she needs?</td>
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<td>2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?</td>
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<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
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<td>4. Do you feel embarrassed over your relative’s behavior?</td>
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<td>5. Do you feel angry when you are around your relative?</td>
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<td>6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?</td>
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<td>7. Are you afraid about what the future holds for your relative?</td>
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<td>8. Do you feel your relative is dependent on you?</td>
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<td>9. Do you feel strained when you are around your relative?</td>
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<td>10. Do you feel your health has suffered because of your involvement with your relative?</td>
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<td>11. Do you feel that you do not have as much privacy as you would like, because of your relative?</td>
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<td>12. Do you feel that your social life has suffered because you are caring for your relative?</td>
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</table>
Carer burden experience in all cultures:

“The demands on me are like weights on my back. They weigh me down. I'm always running and working. The job of looking after someone never ends.” (spouse carer)

Carers Victoria (2003) Beliefs and values about caring in the Anglo-Celtic, Greek, Italian, Polish, Turkish and Vietnamese communities in Victoria

“Pesada” - (Pesado translates to ‘heavy’ in English and back-translates to burdensome in Spanish.) Pesado referred to being physically and emotionally tired from having to manage caregiving with other familial responsibilities. Being pesado for one study participant meant “muerta en vida” or dead in life. She clarified that she felt physically, emotionally, and morally pesado at times when she thought, “How am I doing this and the other?” regarding her multiple responsibilities at home and at work.

Mendez- Luck, C. et al. (2008) ‘Concepts of Burden in Giving Care to Older Relatives: A Study of Female Caregivers in a Mexico City Neighborhood’
Breaking the carer (burden) Dyad

Not about the relationship between carer and those they support. That relationship not central to ‘burden’ (though it can appear that way) Best relationship in the world would be stressful/burdensome under conditions of inadequate & poor

• Sleep/rest
• Time/energy for paid work or education and training or life-long learning
• Time/energy for social engagement, friendships, self care and wider familial networks
• Ability to plan for the future – and envisage a future
• Fragmented & inconsistent (and crisis driven) systems of support
“My daughter is not a burden but caring for her is”
Consultation for Carers Strategy 2017, Carers Victoria

(my emphasis)
Carer organisations are uneasily but also strategically positioned between these three constructions of the problem of carer burden – they collect the evidence of burden and they know how big it is - Carer UK doesn’t pull any punches – ‘Carers at Breaking Point’ (2015)
Key UK findings

6 in 10 carers have been pushed to breaking point

A quarter of those who had reached breaking point required medical treatment as a result

Almost half 46% said they had fallen ill but just had to continue caring

1 in 9 said the person they cared for had to be rushed into hospital, emergency care or that social services had to step in to look after them while the carer recovered.

1 in 5 were forced to give up their jobs because they were in crisis

Carers UK (2014) : Carers at breaking Point
Only 6% of carers expect their quality of life to get better in the next year.

Three quarters (73%) of carers who are struggling to make ends meet say worrying about their finances is affecting their health.

Nearly 6 in 10 (57%) said that they did not feel that they had a choice about providing care to the person following their discharge from hospital.

Carers UK (2014) : Carers at breaking Point
“later life caring involves stresses associated with unending dependency, chronic sorrow, declining physical capacity, lack of formal services, social isolation, financial pressures and anxiety about the future care of off-spring.”

Who will look after her when I die Report on Ageing Carers, Carers Link West, Carers Victoria 2005
Not OK that caring is making people ill – would it be OK if raising children made parents ill?
‘Despite the positive aspects of caregiving caregivers repeatedly claim that they ...”would never wish this on their children”. ‘

‘The conditions of work would be totally unacceptable in a paid work setting’

But wait what about carers and happiness?

Being a carer can be positive and rewarding and deliver sense of wellbeing, and of contribution

- Study in the Netherlands comparing the happiness of carers and non-caregivers, found carers were happier than non-caregivers BUT if the care they were contributing was 6 hours or under per week

- Not all carers doing more than this are ‘unhappy’ what it does suggest is that the time committed impacts on the ability of the carer to negotiate their own and other significant others lives

- Are informal caregivers less happy than noncaregivers?

Impacts of care

• The weekly median income of primary carers aged 15 - 64 was 42% lower than that of non-carers

• More than half (55%) of primary carers provide care for at least 20 hours per week

• 56% of primary carers aged 15 - 64 participate in the workforce, compared to 80% of non-carers

• It is estimated that carers provided 1.9 billion hours of unpaid care in 2015

WPR - Carer Burden as an individual private matter:

If ‘carer burden’ is constructed as individual the responses are individually targeted:

• Respite;
• Carer support workers;
• Carer training;
• Carer support groups;
• Carer education and capacity building - Resilience
‘Managing Stress’ Carers Australia

Identify your strengths and weaknesses

You may be very good at mediating arguments or at switching off worries and thinking about something else. Someone else in your family may be good at finding practical solutions to problems. Build coping strategies around the strengths in your family.

Build resilience

Try to nurture traits that are common in people who respond well to change and adversity:

- look at the funny side of things
- build self-esteem and believe in your ability to cope
- focus on good outcomes and experiences
- accept unpleasantness, learn from it and move on
But if caring is constructed as unpaid work as childcare has been then.....
Care as ‘work’

Fair work practices
- Hours worked
- Safety of work - Skills and training
- Supports
- Leave holidays
- work culture
- Shared capacity
Rather than talking about resilience (which can end up being stoicism or endurance) Can view ‘Carer Burden’ as a consequence of poor work conditions. Carers require care work where conditions are reasonable, accessible and manageable as well as (hopefully) rewarding, meaningful and economically sustainable
Carer burden as a State problem

Carers’ rights legislation that frames:
• Employment flexibility, leave, payments,
• Carer support that is responsive, targeted and whole of family focused
• Carer payment (as income)
Unsustainability of care

Sustainability not just a combination of the:

- Spatial
- Temporal – (time given)
- Relational dimensions of care

But also the accumulation of this activity embedded in the messiness and complexity of families, homes, of the domestic sphere and of changing social economic and cultural relations
‘Hit by a bus’

• What can you imagine might happen if you were ‘hit by a bus’ tomorrow?

• What would it mean for the person you support and provide care for?

Many carers sit with this anxiety about the future all the time
Carers want the person they love & support to be OK, with all the practical, prosaic and existential dimensions of that, without being or feeling completely responsible for that OKness.

Want the person they love & support to have a future with all the practical, imaginative dimensions of that without it completely subsuming or obscuring their own.
Sustainability of care - not just about an ageing population

Functional sustainability

• A lack of systemic support and clear boundaries around what level of responsibility is reasonable, and what is not, in an unpaid carer role.

Socio-cultural sustainability

• A generation of (mainly women) carers whose identity was formed by an expectation that their role was to provide unpaid support to husbands, and children, or to remain in a marriage in sickness and in health, is being replaced by a generation(s) whose identity is invested (amongst other things) in lives that allow them to participate in the workforce, to pursue their own fulfillment, and to negotiate and re-negotiate their personal lives.
Solutions if the WPR is re-engaging the State in the ‘care’ economy.

Responsive services, Peer support, Respite that can be good stuff, care planning and care partnership work

BUT also an integrated approach to building social care & support as a sector and seeing the work carers do as (unpaid) work needing reasonable conditions to be sustainable (for the carer)

Social care, or social service sector as a valuable part of the community rather than a “cost” or impost. The growth industry of the future with the potential to employ, train educate and support carers and care workers,

Currently paid care work is viewed as a ‘welfare problem, as a cost’ and as something carers can do for nothing.(regardless of burden)
Thankyou for listening

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