

Caring in Later Life : Examining the Subjective Understandings of Quality of Life of Older Parent Carers of Adults with Learning Disabilities

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L O N D O N



OVERVIEW

Background

- **Demographics**
- **Research Questions**
- **Key Concepts**

Methodology

- **Approach**

Findings

- **Key Themes and Sub-Themes**

Discussion

- **Indicators from the Data**



BACKGROUND

Demographic Changes

- Increase in Life Expectancy

(Hubert and Hollins, 2000; Grant, 2010)

- Extended Role for Carers

(Cuskelly, 2006)



BACKGROUND

Research Questions

What are the experiences of older parents who provide long-term care for their adult children with learning disability?

How do older parents who provide long-term care for their adult children with learning disabilities conceptualise their quality of life?



CONCEPTS

Caregiving

Difficult to Define:

Arber & Ginn (1990)

Hermanns & Mastel-Smith (2012)

Purpose, Motives & Outcomes:

Nolan et al. (1996)

Quality of Life

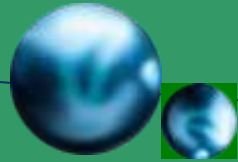
'Slippery' and Difficult to Define:

Rapley (2003)

'Satisfaction with Life':

Moons et al. (2006)

- Contested
- Multifaceted
- Definitional diversity



METHODOLOGY

Interpretive: Constructivist

(Rodwell, 1998).

- Qualitative data from semi-structured interviews with 27 older parents caring for adult children with learning disabilities.
- Data analysis: Framework technique
(Ritchie and Spencer, 1994).



FINDINGS

Overarching themes

1. Enhancing experiences of caregiving and quality of life, despite challenges.
2. Psychological and practical challenges influencing caregiving and quality of life.



Experiences of caregiving	Conceptualisations of quality of life
<ol style="list-style-type: none">1. Enhancing factors of caregiving2. Challenges of caregiving	<ol style="list-style-type: none">1. Positive life appraisals, despite challenges.2. Psychological factors3. Practical struggles



FINDINGS

Theme: Enhancing Factors of Quality of Life.

- Shared Caring / Family Connectedness
- Sense of Purpose
- **Reciprocity**
- Sense of Gratification
- Personal Transformations
- Financial Stability



SUB-THEMES

Reciprocity:

‘It’s good to have someone else in the house now I’m on my own. I don’t always see a lot of him. He’ll come home and as I said have a shower and have dinner. He will stay with me until roughly around about half past seven and I’ll be in here and he’ll vanish in there, and he’ll be playing videos in there. But he’s there, there’s someone in the house. And also he always makes sure all the doors are locked up at night, that’s his job and I let him do it. And we’ve got bird feeders in the garden which my husband used to keep topped up. He has taken over that job, so I let him do it. Because you have to let him do as much as he possibly can. And also if I’ve used something out of the larder or the fridge, anything like that, and I put the packaging in the recycling bin – because we’ve got a recycling bin – the next thing I know he’s taken the packaging out, he’s written down what it is, he’s put the packaging back. He’s got a shopping list! I get given shopping lists. So, I’d miss him terribly if he wasn’t here, because he is good company, he’s good fun. And we can talk about steam railways’. (Mrs Collins)



FINDINGS

Theme: Challenging Factors

- Multiple Losses: Sleep, career, friends
- **Future Care : Fear of Abuse**
- Battles for Services
- **Personalisation / Service Delivery**
- Negative Societal/Professional Attitudes
- Searching for a Diagnosis



SUB-THEMES

- **Future Care: Fear of Abuse**

‘We had reason to believe that he was assaulted. Now, I don’t know if that was behind [our mind] why we found it difficult for him to go to respite unless he is comfortable with the people he’s with’.

(Mr Halcyon)



SUB-THEME

- **Future Care: Fear of Abuse**

My son was getting bullied, physically abused by another client..... It happened in front of me one day..... Even though we were full of anguish, and I said that I don't know what the future has for him and I was wondering what would happen if I die... if both of us [non-disabled son] go, what will happen to my son [with learning disability]. That is the ultimate thing that worries me... it [future] gives me sleepless nights". I know that if he does not go before me. That is my prayer to God. Let him go first. I would go at peace then. If he goes I am quite ready to go If he is here and I die I will die a very tortured. (Mrs Patel)



SUB-THEMES

Policy of Personalisation - Impact on older parent carers:

Additional Responsibilities

‘Direct Payments certainly with my son, awarding him money and saying ok, this is your money...Well certainly, he wouldn’t be able to look after the money himself, so that presents a problem. If he is not going to look after it, then we’ [older parents] will have to look after it’.

(Mrs Carter)



SUB-THEMES

Policy of Personalisation- Impact on older parent carers:

Overwhelming Paperwork and Fear of Getting it Wrong:

'I don't want it. No chance there. Too much paperwork. That's what I tell them. I don't want it. Not a chance you know It does not matter because I don't want that money'. (Mrs St. Bernard)

Stressful and Burdensome:

- *'I honestly cannot take on any more responsibility. I cannot go on chasing who will come and work. They say you will have better control because [you] will be paying them yourself. No, it does not work like that. If I have someone coming and I pay, then suddenly they say I am going home, my son is not well. Then I am completely on my own. I have to find a new one from somewhere else. I can't do that every day I would much rather go to Social Services'. They [Social Services] give me the money and they want me to keep each and every receipt. I don't want all those additional things. I really can't, I have enough on my plate as it is'. (Mrs Patel)*



DISCUSSION

Indicators from Data

- Reciprocity - Manifested in Tangible and In-tangible ways.
(Perkins,2009; Grant, 2010).
 - Challenges the binary of carer and cared for.
 - Highlights that caregiving is not unidirectional.
 - Implications for practice – Dyad/ Triad.



Discussion

Future Care (Fear of Abuse):

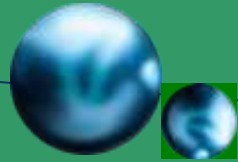
- Propagated by Winterbourne Case
- Sibling Care vs Residential Care
- Adult Safeguarding



Discussion

Policy of Personalisation:

Personalisation is just as much about **stress, burden, anxiety and imposition** as it is about **choice, flexibility and control**.



Key Messages

- The relationship between the delivery of care, the state and the family is changing.
 - Positively Appraise their Quality of Life – ‘Glass is Half-Full.’
 - ‘Experts by experience’ (Scorgie & Sobsey, 2000)
 - ‘Sense of Mastery’ (Perkins, 2009)
 - ‘Sense of Coherence’ (Antonovsky, 1987).
- Offer a Counter Narrative (corrective portrayals) (Redmond and Richardson, 2003) to the Dominant Discourse on Caregiving which Emphasises Care Burden and Stress
(Heller et al., 1997; Minnes and Woodford, 2005).



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THANK YOU

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