



The Caring Reality of Family Carers: An Exploration of the Health Status of Family Carers of individuals with Parkinson's disease

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Summary of Research on Health of Family Carers

- Research on Family Carers' Health in Irl limited
- International evidence more comprehensive:
- Family Carers 3 times more likely to report ill-health than non-carers (Singleton et al, 2002)
- High risk of depression and stress among carers (Boden 2002, Carers UK, 2006)
- Carers unable to participate in social and health types of activities due to burden of care (O'Connell, 2003)
- Irish work has shown caring can take toll on Family Carer's mental, emotional and physical health, with high levels of burden (O'Connor & Ruddle 1988, Blackwell et al 1992, O'Donoghue, 2003).
- Carers Association & Royal College of Physicians (2009): many carers mentally and physically 'drained'

Introduction

- *The Caring Reality of Family Carers: An Exploration of the health status of a specific group of Family Carers*
- Important new study by Care Alliance Ireland in partnership with Parkinson's Association of Ireland
- Aim: to begin to paint a picture of Family Carers, through exploring in a qualitative study, the health and well-being of specific group of Family Carers
- Why? In order to provide improved/effective and targeted/ meaningful supports for Family Carers
- A voice to be given to the quantitative statistics of CAI (2008) study

Objectives:

- To explore Family Carers' of individuals with Parkinson's disease (Pd) perceptions of factors which impact on their health
- To explore Family Carers' of individuals with Parkinson's disease needs in relation to factors impacting on their health
- To explore with Family Carers' of individuals with Parkinson's disease any interventions which they can identify that would contribute to their health status given their particular circumstance

Why Parkinson's disease?

- Parkinson's disease is a progressive neurological condition affecting movement such as walking, talking and writing.
- Symptoms differ– motor (e.g. tremor, slowness of movement, stiffness or rigidity of muscles) and non-motor (e.g. sleep disturbance, constipation, urinary urgency, depression)
- Unpredictable and variable illness trajectory = Heavy physical and emotional burden on Family Carer
- No official figures, PAI estimates over 7,000 individuals with Parkinson's disease in Ireland

Research Project Design

- Participants recruited by Parkinson's Association of Ireland through extensive database of members
- 20 one-to-one interviews conducted with Family Carers providing care to individuals with Pd
- 3/4 Female, 2/3 in 66 year + age category
- With participants' consent, interviews were recorded and then transcribed, emerging themes/codes identified through thematic analysis

Main Findings

4 key themes, various similarities with findings of CAI (2008) quantitative study & other work

1. The Experience of the Family Carer
 - Physical demands & responsibilities, intensified as condition worsened. Emotional assistance also NB. Viewed as long term role
 - Feelings towards caring – expectation, sense of ‘duty’, alternative not possible/ imaginable
 - Challenges – personal care, changes to personality & behaviour, progression of Pd=more demanding role + need for constant physical presence
 - Coping techniques – time to self, personal interests, exercise, friends, support
 - Relationship changes with individual with Pd

Main Findings cont.

2. Impact of Caring – sense of ‘loss’ for life before caring.
Multidimensional impact:
 - Physical – constant presence, change to own daily routine e.g. Working
 - Physical health – high blood pressure, tiredness, loack of physical energy, back problems, arthritis
 - Emotional health – frustration, anxiety, unhappiness, loneliness, depression, expectation to be ‘healthy’, uncertainty over future worrying
 - Social – time to self, hobbies/ interests v. limited. Friendships NB
 - Positive impact also – relationship with individual with Pd

Main Findings cont.

3. Support – multiple sources: formal, informal and financial
 - Both respite services & in house support inadequate for many
 - Diverse experiences with healthcare professionals
 - Support from family valued but varied, sadness and isolation when absent
 - NGOs NB source of accessing info, challenges with support groups identified
 - Levels of financial assistance avail condemned

Main Findings cont.

4. Needs & interventions – time to self NB in maintaining family carers' health & wellbeing e.g. more support from family, respite & day care services, in-house support
 - Support group exclusively for family carers NB
 - Training programmes for family carers crucial intervention. Physical & emotional aspects of caring NB as well as changing & future role
 - Carers' own needs – many did not think about

Key Recommendations

1. Put in place conditions necessary for Family Carers to receive regular and sufficient amounts of rest/ time to self
2. Introduce full assessment of Family Carers' needs
3. Improvements of informal support mechanisms available to Family Carers
4. Introduction of health promotion programme for Family Carers
5. Introduction of public awareness campaign
6. Set education, information awareness and training of healthcare professionals in issues relevant to Family Carers' health as a key priority

Key Recommendations cont.

7. Establishment of an independent Family Carer 24 hour Help Line
8. Provide adequate services to support the health needs of Family Carers in the post-caring phase
9. All policy steps taken to support the health of Family Carers should be proactive rather than reactive

Opportunities for Further Research

1. Exploration of the health and wellbeing of long term Family Carers from a post-caring perspective
2. Detailed investigation of Family Carers' relationships with healthcare
3. Examination of models of good practice of Family Carer supports in other countries

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Findings from the completed quantitative piece of research (2008) are also available to download from our website at:

<http://www.carealliance.ie/documents/CareAllianceIrelandHealthandWellbeingofFamilyCarersNov2008.pdf>