

Carer Education: An Education in SELF (Reflections on practice)

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Early research....

Dementia carer education and patient behaviour disturbance (Coen, R.F., O'Boyle, C.A., Coakley, D., Lawlor, B.A)
International Journal of Geriatric Psychiatry

Volume 14, Issue 4, pages 302-306, April 1999

Conclusions:

The programme increased carers' knowledge about dementia, but had no significant impact on QoL, burden, or well-being. Increased patient behaviour disturbance appeared to be a major factor when the carer's situation worsened over time. Despite high carer satisfaction the efficacy of a group-based education approach to the management of behaviour disturbance in dementia appears limited. More intensive or individually tailored interventions may be necessary alternatives.

When a little knowledge is a dangerous thing....: a study of carers' knowledge about dementia, preferred coping style and psychological distress (Proctor, R., Martin, C., & Hewison, J)

International Journal of Geriatric Psychiatry Volume 17, Issue 12, December 2002

- The aim of this study was to improve understanding of the relationship between carers' existing knowledge about dementia, their coping style and psychological morbidity.
- The results indicated that carers who demonstrated more knowledge about the biomedical aspects of dementia were more anxious ($p < 0.05$). Furthermore, carers who had a preferred coping style of monitoring for threat relevant information were more anxious ($p < 0.005$).
- Understanding more about those factors that are associated with knowledge about dementia will help to identify profiles of carers who are in need of education and in matching individually tailored interventions to carers with specific learning needs. Copyright © 2002 John Wiley & Sons, Ltd.

Effect of a training programme to reduce stress in carers of patients with dementia.

BMJ 1989; 299 doi: <https://doi.org/10.1136/bmj.299.6712.1375>
(Published 02 December 1989)

- To reduce the psychological stress and improve the skills in coping of people who care for relatives with dementia. Eligible patients were less than 80 years old, had mild to moderate dementia, and lived at home with their carer.
- Patients & carers were allocated to groups; 33 were in the dementia carers' programme group, 31 were in the memory retraining group, and 32 were in the wait list group. Reassessment at three, six, 12, and, for those in the "wait list" group, 18 months. The programmes were conducted in the psychiatry unit of a Sydney teaching hospital.
- Carers in the dementia carers' programme received training in coping with the difficulties of looking after patients with dementia while the patients had sessions in subjects such as memory retraining. In the memory retraining programme patients were admitted and received the patient component of the carers' programme while their carers had 10 days' respite. In the wait list group carers waited six months before undertaking the carers' programme.

➤ **MAIN OUTCOME MEASURES**—Effect of the programmes on carers' general health questionnaire scores and the rate of placement of patients in institutions.

➤ **RESULTS**—At 12 months' follow up the carers' programme had resulted in significantly lower psychological stress among carers than the memory retraining programme. In the wait list group distress scores remained stable, even after the carers and patients had undertaken the carers' programme. Patients deteriorated over 12 months regardless of group allocation, but at 30 months, allowing for patients who died and could not be included in the analysis, 65% of patients in the carers' programme group were still living at home compared with 26% in the memory retraining programme group.

➤ **CONCLUSION**—The intensive intervention programme described for carers of patients with dementia can reduce the psychological morbidity of the carer and delay the placement of the patient in an institution without increasing the use of health services by either patient or carer.

Some Learnings

- Knowledge... had no significant impact on QoL, burden, or well-being.
- More intensive or individually tailored interventions may be necessary alternatives.
- Carers who demonstrated more knowledge about the biomedical aspects of dementia were more anxious
- The intensive intervention programme described for carers of patients with dementia can reduce the psychological morbidity of the carer and delay the placement of the patient in an institution without increasing the use of health services by either patient or carer.

Old Age Psychiatry Team

- Full complement of disciplines: Psychiatry, Social Work, Occupational Therapy, Community Mental Health Nursing, Clinical Psychology
- Carer in from the start as part of collateral/assessment
- Assessment of coping, distress
- Referrals made at team meeting following discussion re the best person for the job based on current priority in the case
- Range of overlapping and professional specific initiatives

History of Carer Education in OAPsych

- Responding to the expressed distress of carers
- Informal... case by case to families & formal (paid) carers (nursing home).
- Not co-ordinated.
- Frustration at the repetition of information
- 2004 'Nursing Home Education Project'

Education Programme 2004

Mental Health And Older Adult Care
 Thursday 28th October and Thursday 4th & 11th November 2004.
 Time: 2-4pm (lunch from 1pm)
 Venue: Education and Research Centre, St. Vincent's University Hospital, Elm Park, Dublin 4.

Content of Sessions

28/10/04	Dementia Depression Bereavement & Loss Independence/Dependence
4/11/04	Person Centred Care Meaningful Activity Challenging Behaviour
11/11/04	Delirium Family Involvement & Legal Issues Staff Stress



Nursing Home Education 2009

- *Unit 1* Understanding Human Behaviour
- *Unit 2* Dementia as Disability
- *Unit 3* Relationships & Personal Responsibility
- *Unit 4* Preventing Difficult Behaviour
- *Unit 5* Working Confidently with CB
- *Unit 6* Functional Assessment

Why are we talking about Carer Education?

Zarit & Zarit (2014 DSICD conference)

“Caregiver interventions are vital as dementia care is the most challenging kind due to the continuous ongoing stress on carers”

DISEASE ----- BEHAVIOUR & CARE ----- DISTRESS/BURDEN

- To decrease burden among carers
- To decrease health risks in carers
- To reduce premature mortality

What are we talking about?

- Imparting knowledge about...
Illness & Behaviour problems/ Stress/ the importance of self care/ services available
- Problem Solving
- Skill training
Behavioural observation
Managing specific BPSD through the integration of scientific knowledge & intimate knowledge of the person
- Stress reduction & Self-care through
Training in stress & anxiety management, Mindfulness.
Time off to increase resilience (support)
- Self Knowledge through the experience of care

Characteristics of Effective Interventions

(Zarit & Zarit)

- Psychological vs Educational
- Multidimensional vs uni-dimensional
- Flexible vs rigidly scripted (addressing the goals that are important to carers)
- Family Focus
- Targeted treatment at the appropriate dosage
- Treatment is often short-term but caregiving is long-term (literature lacks this understanding)
- Carer programs across the career of caregiver (developmental)

Components of Effective Interventions

- Goal Setting (based on individual need)
- Increase Understanding
- Skill Building
- Increasing Support & Family Help
- Using formal support

DSICD Conference 2015 Some learnings

- Partnership with Families
- Site specific teacher from the same setting
- Support for caregivers
- Targetted education that is face to face, interactive, problem-based case learning
- Organisational change

Systemic/organisational interventions

- Site specific teacher from the same setting
- Support for formal caregivers
- Targetted education that is face to face, interactive, problem-based case learning
- Organisational change



The Help?



Nursing

- Carer Transition Group for spouse/life-partners who are negotiating long-term care or the PwD has just gone into care.
- Peer supported/facilitated discussion around LTC.
- Focus on where the carer is at NOW; roles change; maintaining positive relationships & memories; how N/Hs work; moving on with life alongside LTC entry
- Networking effects
- Giving caregiver information re options/services available/ linking with support groups in the community
- Living Well with Dementia programme (speaking at meetings as part of this programme)

Nursing

- Identifying BPSD and unmet needs/problem solving & finding solutions
- 1:1 training with staff around managing difficult situations
- Group training for responsive behaviour
- Individual support to families around progression of dementia; changes in role
- Practical information/advice to a family member re meeting the needs of the PwD and with understanding their reality
- Education re signs of delirium and what to do

Occupational Therapy

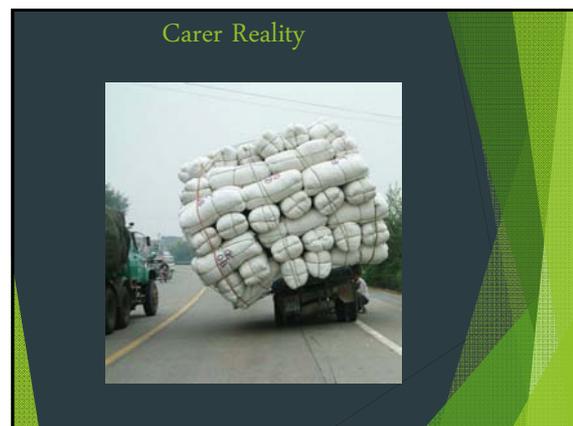
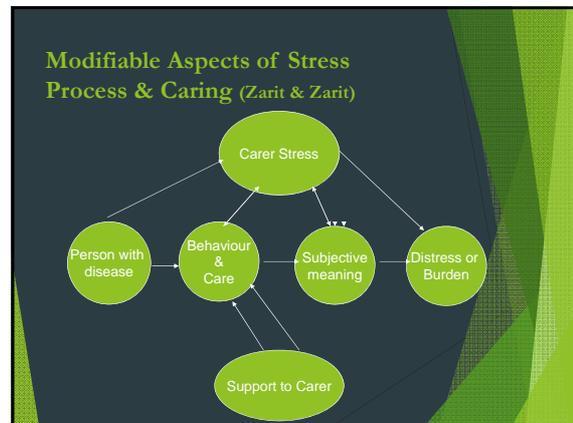
- Formal intervention following direct referral from MDT member for...
 - Anxiety Management
 - Mindfulness for better self care and responsiveness vs reaction to carer stress
- Informal as part of Home safety assessments of PwD where carer burden is identified. Intervention in the form of practical advice incl education and signposting towards avenues for support (ASI Cafés, talks, LWd Forum); exploring the possibility of delegating care tasks; encouraging the carer in their own supports & leisure; communicating with CMHN to reinforce this & follow up
- “Top up”/maintenance through telephone support; reviewing techniques & making minor changes to get back on track
- Referral on to MDT members

Social Work

- Make the social work service accessible to many carers
- Individual & Group based interventions (emotional & practical)
- Group Carer Support Programme (up to 2013) to give information (LTC, Community Support Services, Financial, Legal Issues) *Currently Carer Support Group*
- Facilitating carers to meet others in similar situations to
 - & mutually support, advise & help each other
 - To address carer stress & isolation
- Workshop ‘Helping Families Through Major Transitions’
- 1:1 work to listen, provide tailored information & advice, advocate, help with role adjustment, and identify coping strategies to deal with carer stress
- Teaching to carers in training on communication skills to deal with family members & carers

Clinical Psychology

- ▶ Referrals to Clinical Psychology are made for Carers who are 'stuck' and struggling beyond the efforts of other input by members of the MDT
- ▶ Issues mostly lie in their *emotional* experience of what is happening and therefore requires an *emotional* intervention
- ▶ Intervention goes beyond emotional support that includes acknowledgement of feelings/situation



Factors within the carer that impact on their emotional experience of caring

- ▶ The amount of additional physical demands that stress the person
- ▶ Different tolerances and stress response
- ▶ Resulting in a confrontation with an emotional self
- ▶ History of emotional coping style particularly avoidance
- ▶ Linked to emotional learning
- ▶ Previous history of dealing with emotional problems in an **emotional** way

Factors within the carer that impact on their emotional experience of caring

- ▶ History of trauma that can facilitate coping or have a wearing effect
- ▶ Exploring conditions on self & attitudes to self in terms of compassion or criticism
e.g. "I'm failing" "I'm letting down"
- ▶ Changes in the nature of the relationship with the person being cared for (may include role reversal)
- ▶ Changes in the reciprocal nature of the relationship
- ▶ Changes to own life resulting from these changes...social network/outlets

Factors within the PwD that impact on the emotional experience of the carer

- ▶ Direct impact of behaviours on the relationship
 - Memory Difficulties
 - Executive difficulties (apathy, disinhibition, lack of initiation)
 - Communication difficulties
 - Difficulties with empathy and relating
 - Body Clock disturbances
- ▶ Social withdrawal resulting in a reduction in social network and activities
- ▶ Feelings of infantilisation
- ▶ Previous Personality

Factors within the Carer & PwD

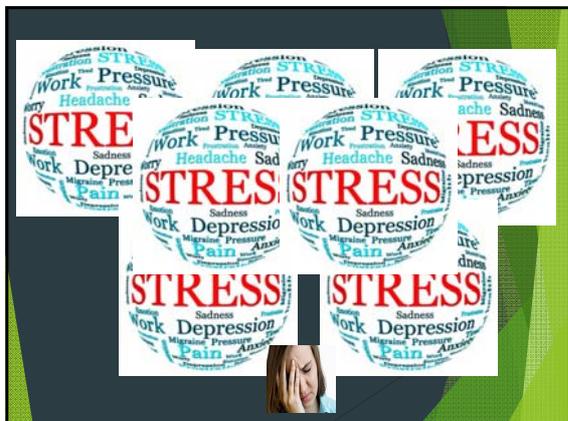
- ▶ Role loss & change
 - Exploring PTSD model.
 - People still adjusting EMOTIONALLY to a diagnosis even after practical adjustment has been made. This can go on for a very long time
 - Parallel processes but not at the same rate/speed
- ▶ Attachment Issues



- ▶ Assess the balance of needs being met
- ▶ Reinforce the importance of carer well-being
- ▶ Define stress & identify the particular sources of it (case by case)
- ▶ Identify the carer's emotional experience (sadness, anger, denial...)

Emotional Experience (Carer)

- ▶ Drained
- ▶ Overwhelmed
- ▶ Sad
- ▶ Angry
- ▶ Frustrated
- ▶ Lonely
- ▶ Irritated
- ▶ Afraid
- ▶ Disappointed
- ▶ Abused
- ▶ Abandoned
- ▶ Insecure
- ▶ Resentful
- ▶ Guilty



Definition of Stress and Strain

- When external forces are applied to objects made of elastic materials, they produce changes in shape and size of the object.
- Strain is the relative change in shape or size of an object due to externally-applied forces.

Stress is the internal force (per unit area, etc.) associated with a strain.

Hooke's Law: Stress is directly proportional to strain.

Keep definitions simple & unambiguous!

Stress is when the number of things bearing down on an object are greater than the capacity to bear them resulting in strain

Allow for Emotions to be Acknowledged!

STRESS!
 the confusion created when the mind must override the body's basic desire TO CHOKE
 THE LIVING CRAP OUT OF SOME IDIOT WHO DESPERATELY DESERVES IT!

- ▶ Explore the carer's perception of their coping. How accurate is this?
- ▶ Explore the carer's history of coping.
- ▶ Explore the carer's history of caring.
- ▶ How is this acting for or against the carer?

