

Family-centered counselling for carers of people with dementia

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Background

- Home care predominantly
- One million home carers
- \$6.5 billion annually
- Preferred option
- Significant psychological, physical, social and financial demands
- Potential to last for many years
- Negative effects continue for months, years, after death of person with dementia

Background

- Depression
- Reduced life satisfaction
- Increased physical health problems
- Increased responsibilities lead to changes in relationships
- BPSD
- Risk of isolation

NYUCI

- New York University Carer Intervention (NYUCI) - specialised counselling training for health workers with a focus on helping family members of people with dementia manage the challenges of caring.
- High quality evidence shows it helps carers mobilise and utilise their social support networks with significant positive outcomes for both the carer and person with dementia.

Intervention Overview

- comprehensive assessment
- six sessions of face to face individual and family counselling
- support group participation
- additional counselling by telephone as needed.

NYUCI (Aus)

Year 1: Developed an innovative Internet-based Multimedia Education (IBME) program for the NYUCI, trained 25 Blue Care workers in the NYUCI and evaluated the IBME program.

Year 2: Offered dementia carers the opportunity of participating in the NYUCI program.

Year 3: Evaluating effectiveness of NYUCI program.

NYUCI-AUS Preliminary data



Carer / Intake sessions:

- Qualitative responses gathered from counselling notes indicate that carers experience anxiety about the future – e.g. ability to care for relative, finances, nursing home placement
- Experiencing grief over the loss of relationships with relative (e.g. reports of 'feel the loss of mum or husband/wife'); feeling that they have fallen out of love with their partner
- Carers experiencing depressive symptomology; low (self-rated) quality of life



NYUCI-AUS Preliminary data



- Carers report that they 'frequently feel stressed' between caring for their relative and trying to meet other responsibilities
- Carers feel frustrated with their relative and experience guilt over their feelings of frustration
- In some instances carers are concerned for financial burden of placing their relative in a nursing home and are looking for information, strategies and social support to assist them with caring for their relative in their home as long as possible
- Anecdotal reports from family carers are that they do not wish to burden those close to them who could potentially provide emotional and tangible social support



NYUCI-AUS Preliminary data



Post (follow-up) sessions:

Following sessions with NYUCI-AUS counsellor, carers report:

- Feeling more comfortable with ability to care for their relative;
- Feeling more positive about getting into contact with family members for support (that they would otherwise felt were 'too busy' or 'estranged')
- Find the sessions helpful because they feel that someone 'understands' them



NYUCI-AUS Preliminary data



Quote from a respite worker who is referring carers:

- “when I told [carer] about the program and whether [carer] would like to go into the program with you, she nearly begged ...”



Where to from here...

- Roll out nationally
- Set up a national database
- Form an international community of counsellors
- Funding to adapt for different groups, i.e. IHWs and indigenous family carers

NYUCI (IHW)

Year 1: Develop an innovative Internet-based Multimedia Education (IBME) program for the NYUCI-Aus, train ??12 Indigenous Health Workers in the NYUCI and evaluate the IBME program.

Year 2: Offer dementia carers the opportunity of participating in the NYUCI program.

Year 3: Evaluate effectiveness of NYUCI program.

COMMENTS ?????

Thank you for your attention: