

Community Care of Informal Caregivers of Those With Dementia

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Why be concerned about caregivers?

Is There A Rationale For Formal Health Policies And Clinical Programs for Caregivers?

Family carers are essential to the dementia care infrastructure but usually have inadequate knowledge and skills



Profile of Canadian Carers

- 97% with dementia have at least 1 carer.
- Majority of informal carers are individuals within the patient's own family
- 70% women (29% wives 24% daughters)
- Carers are older: 50% > 65 yrs; 36% > 70



Barry Russell (center) spends 10 to 20 hours a week caring for his mother, Patricia Franklin, and his step-father, John Franklin.

- (Alz. Soc Canada 2010; Statistics Canada, 2003 General Social Survey; Canadian Study of Health and Aging Working Group, CMAJ 1994; 150 : 899; Statistics Canada, www.statcan.ca).

Economic Cost

Replacement /imputed costs for unpaid carers

- Can 2009 **CAD \$25-\$26 billion** (Hollander et al 2009) (total Health Care Expenditure 10% of GDP ≈ \$133 billion)
- UK 2007 - **£87 billion** (Buckner and Yeandle 2007)
- US 2006 - **US\$354 billion** (Gibson and Houser 2007)
- Aus 2005 - **A\$30.5 billion.** (Access Economics Pty Limited 2005)

Disproportionate Physical Risks

- Higher prevalence of **physical symptoms** than non- carer peers
- More **doctors visits**; higher rates of **prescription drug use** .
- poorer subjective **ratings of health**
- Compromised **immune** function; **Heightened stress response**: Caregiving for AD: 4 x rise of IL-6
- Exacerbation of pre-existing **illness**- diabetes, hypertension other cardiovascular diseases.

\ (Alberts et al, 2011; Baumgarten et al.1992; Gaugler et al, 2010; Gusi, et al, 2009; Hooker, 1992; Katon et al, 1982; Kiecolt-Glaser 2011;1987; Lee et al 2003; Pruchno 1989; Robison et al 2009;

Schulz 1995; Vitaliano et al 2003)

Disproportionate Psychological Risks

- Higher rates of **depression** (14 –47%).
 - 10% meet DSM criteria for depression
- 7 –31% take **psychotropic meds**
- More likely to suffer a **relapse** of pre-existing psychiatric illness
- More likely to over-use substances such as **alcohol**.
- **Emotional vulnerability: anxiety, grief, guilt, rage**
- (Akkerman & Ostwald 2004; Alspaugh et al 1999; Baumgarten et al, 1992; Brown et al. 1990; Burns & Rabins, 2000; Coon et al, 2003; Dura et al 1991; Saad et al. 1995; Schulz et al, 1995)

Defining Caregivers and responding to their needs

Not as obvious as it may seem

Scarce Studies that explore the definition, daily challenges and experiences, and the needs of ADRD carers from their own perspectives .

Professionals often impose their own goals on caregivers leading to mismatch between interventions for caregivers and their needs or risk factors.

(Zarit & Femia, 2008; Borrayo et al., 2007; Hepburn et al., 2002)

Family caregivers first see themselves as spouses or as children

This is more than semantics. It helps to define the range of **needs** and the reasons for caregiver **burden** and is one of the reasons for mismatch of **services** and

- Caregivers are widely diverse as are communities
- Ethnocultural diversity – Chinese and Tamil- issues of stigma
- Services and partnerships- what are the core issues
- Intergrated system based on clear definitions and models- felxibly delibvered at point of care.
- Defining the caregiver- care managing and daily care

Challenges of a spouse dealing with dementia

- Complex technical practicalities, instrumental support ,
- **Debilitating emotional factors- Self expectations**
- **Skills and knowledge deficits**
- Chronicity and increasing severity of illness
- All encompassing and consuming role-entrapment
- Family and social management
- Professional support and expert medical care

Non- Instrumental Challenges of a spouse dealing with dementia: clues to a sustainable homecare system

Challenges

- **Adapting to impaired partner** – “undoing the relationship” role reversal; solo decisions, supervision, lost companionship, lost confidant
- **Intense emotions:** Guilt, anger, frustration, Anxiety, Depression, Shame.
- **Isolation** – social and family
- **Unwelcome New self perception:** altered/uncertain future; trapped forever; bewildered; “a neutered object”

Outcome

- Emotion Focused coping
- Denial of disease
- Undue Self expectations
- Loss of self efficacy and control
- Withdrawal and avoidance
- Inability to give up or plan for future
- Personal risk

Refining response to Needs of Caregivers

- **Systematically address emotional needs**
 - **Care Centres** for at home caregivers
 - **Skills training (cannot be separated from emotion interventions)**
 - Anti-stigma interventions
 - Training Centres for mental health providers to deal with carers.
 - professional support network
- **Instrumental System response**
 - address chronicity and disease progression – the moving target approach
 - **Flexible substitute care**
- A clear utilization **roadmap, guidance system and brokering service** to the social and home support network, and the professional response network legislation and policy,
- **Formalize a Caregiver Policy** – include skills-training, family system breakdown and key emotion-based barriers to effective care

The Reitman Centre
“CARERS”
Program™
(Coaching, Advocacy, Respite, Education,
Research, Simulation)

This project is funded in part by the Government of
Canada's
Social Development Partnerships Program"

The Reitman Centre Offers Comprehensive Short and Longer Term Caregiver and Care Recipient Clinical Services

- **The Reitman Group Program**
- Comprehensive Geriatric Psychiatric Services
- (Memory Clinic Assessment and Treatment)
- Individual / Family Assessment and Intervention

Evidence-based Clinical Goals for CGs

- Enhanced **practical skills** through training
- Improved **coping/problem solving** through knowledge
- Improved **emotional regulation**; sense of isolation
- Enhanced sense of **mastery/self-efficacy**
- Reduced **depression/anxiety**.
- Improved **social (marital) interaction/support**
- Adequate **professional support**

Acton et al 2001; Brodaty et al 2003; Burns et al 2001; Gitlin et al 2003; Kneebone et al 2003; Pusey et al 2000; Schultz et al 2002; Smits 2007; Van den Wijngaart 2007

2 Basic Methods (Manualized)

Cognitive –appraisal,
Problem solving



4 **PST** Groups
(2.5 hours)

Skills,
Self efficacy, mastery



6 Skills training
Simulation Groups:
CGs practice new
Techniques of
Interaction and
communication
during enactments
with SPs

Caregiver Outcome Measures

- **Coping:** Coping Inventory for Stressful Situations (Endler & Parker, 1990)
- **Emotional Regulation :** Five Minute Speech Sample (Magana et al., 1986)
- **Mastery :** Mastery (Pearlin & Schooler, 1978)
- **Caregiving Competence** (Pearlin et al., 1990)
- **Role Captivity** (Pearlin et al., 1990)
- **Role Overload** (Pearlin et al., 1990)
- **Depression:** GDS (Yesavage & Brink, 1983)
- **Social Support:** The Loneliness Scale (De Jong Gierveld & Tilburg, 1990)
- **Health:** Cumulative Illness Rating Scale for Geriatrics (Miller, Paradis & Reynolds, 1991)
- **Personality / Attachment:** Relationship Scales Questionnaire (Griffin & Bartholomew, 1994)
- **Caregiver Burden:** Burden Interview (Zarit,)

Example of a 1st Group Problem list

- *Getting out of the house (caregiver)
 - Spouse's safety while away
- *No one to talk to; support system
- *How do I cope or react? Acting in ways we don't like
- *Frustration, and how to handle it
- Lack of continuity (cannot follow thought processes, no planning)
- Different abilities among types of memory
- Disorientation to place and time
- Change of personality; personality traits
- Spouse's response to suggestions
- One-track thoughts
- *Repetitive questions/statements
- Genetic component (Parkinson's symptoms)?
- Medications not helpful
- *Short-term memory deficits
- Not driving
- Choice of clothing; not changing clothes; dressing appropriately for weather; having to dress spouse
- Need for consistency/stability
- Others treating spouse differently
- Disinhibition/no control
- Obsessive compulsive behaviours
- Unable to reason
- Inability to manage medications
- Worries about wandering
- Getting spouses attention
- Confusing reality with dreams
- Seeming 'blank'
- Spouse worries/is anxious about plans for the day
- Spouse's frustrations/fears
 - Understanding their perspective and feelings
- *issues regarding outside help/support
- Forgetting when they have eaten; preparing meals at the wrong time; preparing food/drink in general
- Hygiene/bathing – cueing for these activities
- Sleeping: at night and during the day; more alert when engaged/interested
 - Finding activities of interest
- Apathy

Scenarios crafted to simulate and practice different interactional and communication Themes

- Responding to *Accusations* against the caregiver
- How to say *no* to unreasonable demands
- Dealing with *confusion, opposition and resistance*
- Dealing with *repetitiveness, angry outbursts, eating and feeding*
- *Telling others* about the illness of their loved one.
- Moderating *angry expectations* of carer.

Emotional challenges and barriers to change were part of all discussions

- Loss of the prior relationship
- Coping with the 2 realities of the relationship
- Loss of oneself
- Shame, guilt, ambivalence
- Sadness, loneliness; unresolvable grief
- Time pressures
- Entrapment
- “My life as a neutered object”; “decisions are life and death”; “thinking for 2 all the time”

Carers reflections on Lessons Learned

- Ask their feeling- understand
- acknowledge his her perspective
- Accept that he/she is not who he/she was and cannot do what they did before
- Use statements and avoid asking questions
- Listen to his/her side, respect and validate his/her capability
- Pause before speaking or acting.
- Try to be patient
- Pick your battles
- logic often impossible
- Learn to ask for help, it's OK to ask for help.
- Accept more help - you can't do anything on your own.
- It's OK and necessary to take care of yourself.
- Acknowledge your own feelings of anger, denial, grief
- "I am not so alone"
- Education about the disease – changes in cognition and physical health
- "Wires do not connect anymore".
- Comprehension is impaired.
- Execute capacity power of attorney as needed.
- Involving family - grandchildren can be valuable allies
- "more on our shoulders"
- Do with him/her not to him/her, when possible.
- Relate to heart not to head
- Learn about resources available
- Anticipate the future.

Overall findings (n=37 carers)

- Pre- and post- scores were significantly different for these 2 constructs:
 - **Emotion-oriented coping style (CISS)** (mean dif = -3.03 p<.05)
 - **Caregiving Competence** (mean dif = 1.30, p<0.01)
- The rest of the studied constructs, showed **trends in the direction of the intended effects** of the CARES program. A larger N will be required for significance to show

Clients' Satisfaction: Clinical Components

- 100% of them agreeing that their coping and problem-solving skills were improved after the program.
- 92.3% agreed the focus on emotions in care-giving was helpful,
- 84.6% agreed that they are more confident dealing with care-giving challenges after the program.

Clients' Satisfaction: Simulation

- 88.5% agree that the simulations were useful.
- 80.8% agreed practicing the same simulations repetitively was helpful
- 84.6% agreed the simulations accurately portrayed the problems encountered at home.

Some Key Outcomes

- Skills training changed their behaviour and attitudes and feelings about care recipient
- Many specific problems were solved – driving; alcohol
- Practicing and repetition were among the most helpful interventions
- Heterogeneous groups are acceptable
- Professional support highly valued as was camaraderie of the group
- Maintenance- 1 hour group/month