Mental Health of Family Caregivers: A Review of Empirical Evidence and Practice Implications

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Who is a “family caregiver”?
An individual who is currently providing in-home care to a family member who has a physical or mental disability, is chronically ill or is frail (excluding short term care involved in injuries or illness)

(Health Canada, 2002)
What do we know about family caregiving?

**Alberta:**
- Almost 1 in 4 Albertans over 45 are caring for a senior  
  (University of Alberta, 2007)

**Canada:**
- 8.1 million (28%) Canadians aged 15 and older are family caregivers
- 48% of caregivers provide care to aging parents and parents in-law  
  (Statistics Canada, 2012)
What do we know about family caregiving?

• In 2012, 54% of Canadian caregivers and 66% of American caregivers were women (Family Caregiver Alliance, 2012; Statistics Canada, 2012)

• ~44% of Canadian caregivers were aged 45 to 64 in 2012 (Statistics Canada, 2012)

• Performing caregiving tasks is associated with decreased physical and mental well-being and increased social and financial burden (Lai & Leonenko, 2007; McCallum, Spencer & Goins, 2008)
Why is family caregiving important?

For care recipients:
• Aging in place
• Deinstitutionalization (Aneshensel et al. 1995; Cantor 1991)

For family caregivers:
• Contributing to the family
• Competence

For the health care system:
• Economic value of ~$450 billion in the US in 2009 (National Alliance for Caregiving and Evercare, 2009)
• Valued at ~25 billion in Canada in 2009 (Hollander et al., 2009)
Academic research on family caregiving

Topics and focuses:
- Caregiving and relevant consequences
- Culture and family caregiving
- Employment and family caregiving
- Interventions for family caregiving

Research populations:
- Most studies based on Caucasian populations
- Studies on visible minorities and immigrant population are increasing (Knight et al. 2007; McCallum et al. 2008)
Theoretical frameworks

Caregiving and the stress process model
(Pearlin et al., 1990)
Theoretical frameworks

Socio-cultural stress and coping model
(Knight et al., 2000; Knight & Sayegh, 2010)

• Race and ethnicity are included in the model.
• Different coping strategies
• Cultural values play key role in the model
Impacts of family caregiving

Widely studied issues:
• Caregiving burden
• Physical health consequences
• Mental health consequences
• Cognitive impact
• Employment
• Social interaction
• Service utilization
• Intervention programs
Impacts on mental health

• Most studies reveal negative effects on mental health

• Different aspects of mental health:
  – Depression, distress, anxiety, other psychological symptoms
  – Depression is the most widely examined
    • Center for Epidemiologic Studies Distress Scale (CES-D)
    • State-Trait Anxiety Inventory (STAI)
    • Brief Symptom Inventory (BSI)
    • Geriatric Depression Scale (GDS)
Impacts on mental health

• In most studies, caregivers report poorer mental health than non-caregivers (Gallagher-Thompson et al., 2006; Hahn et al., 2011)

• Mental health condition may change after becoming a caregiver
  – Focus on different time periods (6 months, 12 months, etc.)
  – Impacts of significant events
  – Utilization of social support and services or intervention programs
Mental health outcomes among different ethnic groups:

- Caregivers from African ethno-cultural groups reported the best mental health (Montoro-Rodríguez et al., 2007; Morano & King 2005)
- No clear conclusions for other ethnic groups
- Limited research on mental health of caregivers from ethno-cultural groups
Predictors and risk factors

• Care recipients’ characteristics:
  – Health conditions (e.g. impairment, problem behaviors) negatively related to caregiver mental health (Chun et al., 2007)
  – Dependence level (ADLs, IADLs) (Herrera et al., 2009; Lai, 2009)
  – Hospice or hospital living condition

• Dementia caregiving → dementia anxiety (Alberts et al., 2011)

• Mortality communication and caregiver depression (Bachner et al., 2009)
Caregivers’ characteristics

• Health conditions
• Demographic background: age, gender, education level, etc.
  – Results vary across studies, different samples
• Mastery level: knowledge of caregiving, role overload, role captivity, attitude to caregiving role
• Coping strategies: negative strategies, religious strategies, etc.
Socio-economic factors

Social resources:
• Available support from family, community, and professional agencies (formal/informal)
• Utilization of social services

Economic status:
• Employment status
• Work-family conflict
• Financial situation
Relationship between caregivers and care recipients

Kinship:
- Children, children-in-law, spouses
- Mixed results across different studies

Living arrangement:
- Caregiving intensity
- Support from other family members
- “Sandwich” generation

Relationship quality
Family level factors

• Care recipients’ involvement in family life
• Family capacity to deal with family issues such as conflict
• Both family involvement and capability are positive predictors
• Limited studies on these issues

(Mitrani et al., 2005, 2008)
Significant events

Death of care recipients

- Caregivers experienced improvement in health risk behaviors (Schulz et al., 2001)
- Depression and distress highest during caregiving period, and the first few months after death (Chentsova-Dutton et al., 2002)

Nursing Home Administration (NHA) of care recipients (Gaugler et al., 2009)

- General decrease in caregiver burden and depression
- Older and female caregivers benefit less from NHA
Socio-cultural influences on caregiving

Family caregiving among visible minority and immigrant groups:

- Roughly 20% of African American, 18% Asian American and 16% of Hispanic American are engaged in caregiving (National Alliance for Caregiving, 2009)
- Specific cultural values have different influences on caregiving stress and coping (Knight et al., 2007, 2010)
Cultural influences on caregiving

Familism and filial piety (Chun et al., 2007; Losada et al., 2007)
• Two different concepts
• Responsibility or affection?
• Attitudes towards family caregiving

Stigma of certain diseases (AD) and aging
• Lower use of social support or formal services (Lai, 2007; Pinquart & Sorensen, 2005)
• Coping strategies tend to be negative (Pinquart & Sorensen, 2005; Spitzer et al., 2003)
Cultural influences on caregiving

Acculturation of visible minorities (Hahn et al., 2011)

• Education and Westernization
• Mainly focus on adults children’s attitudes toward caring for aging parents

Language competency

• Positively related to mental health (Lai, 2009)
• Related to service utilization and social support
Cultural influences on caregiving

Attitudes towards the health care system
- Different cultural beliefs about health care services
- Stigma related to certain diseases

Barriers to health and social care access (Lai & Surood, 2009)
- Cultural incompatibility
- Administrative problems
- Circumstantial challenges
- Negative perception toward services
- Personal attitudes
Mental health implications for minority and immigrant caregivers

- Double dilemma: immigration experience and family caregiving experience
- Inequality in health care accessibility
- Immigrant health effect
- Social integration and health outcomes
Practice responses to caregiver mental health

Key recommendations from previous research:

Formal/informal support:
• Understanding of cultural preferences for social support
• Different forms of social support: religious support, home care support, etc.

Caregiver-care recipient relationships:
• Support to empower the caregiver to understand care recipient situation and perform caregiving tasks
Practice responses to caregiver mental health

Socio-cultural factors:
• Cultural sensitive services
• Community based support
• Ethno-cultural staff in health and social care system
• Easy access (language, affordability)

Future research directions:
• Clarify relationship between mental health and different predictors
• Further examine racial differences
Key intervention program components: Best practices

Psycho-education:
• Stress management
• Problem solving (coping) skills
• Self care skills
• Caregiver’s manual

Information support:
• Knowledge of care recipient disease and other health conditions
• Information on available resources
Key intervention program components: Best practices

Support groups:
• Regular support group meetings with other caregivers
• Support from professional staff (e.g. social workers)

Family supports:
• Home care
• Day programs
• Home safety assessment and modifications
Key intervention program components: Best practices

Counseling:
• Use of new technologies:
  – Telecommunication, videophone, etc.
• Ad hoc telephone counseling

Other interventions:
• Care managers and care planning
• Role-playing
• Financial assistance
Example of an intervention program: REACH II

Resources for Enhancing Alzheimer’s Caregiver Health II

- American program
- Sample: White (n=219), African American (n=211), Hispanic or Latino (n=212) caregivers
- Interventions: 12 home sessions, telephone sessions, and support group sessions
- Education about Alzheimer’s disease, role playing, problem solving, skills training, stress management techniques

(Hatch et al., 2013)
Outcomes:

• Participants reported reduced depressive symptoms
• Participants with higher depression and stress levels at baseline benefited more from intervention
• Participants who had paid homemakers and home health aides also benefited more

(Hatch et al., 2013)
Effects of intervention programs

- Generally positive outcomes for caregivers
- Different intervention types have different effects (Gallagher-Thompson et al., 2003)
  - “Coping with caregiving” class
  - Enhanced support group
- Older caregivers benefit more (Winter et al., 2007)
- Spousal caregivers benefit more (Belle et al., 2006)
- Caregivers with higher stress and depression benefit more (Hatch et al., 2014)
Effects of intervention programs

• Outcomes related to ethnicity:
  – Members of African groups benefit the least, compared to other ethno-cultural group (Belle et al., 2006; Elliott et al., 2010)
  – Interventionists from the same ethnic or racial background associated with greater improvement in caregiver mental health (McGinnis et al., 2006)

• Interventions focusing solely on care recipients: no effects on caregiver mental health (Sherwood, 2012)
Recommendations

Research recommendations:
• Clarify the relationship between mental health outcomes and predictors (direct/indirect)
• More research on visible minorities and immigrants and the influences of socio-cultural factors

Practice recommendations:
• Identification of evidence based practices
• More cultural sensitive services for visible minority and immigrant groups
QUESTIONS?

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