

RESEARCH SNAPSHOT

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WHAT'S NEW?

The monthly Research Snapshot provides an overview of recent research publications related to the work of Carers NSW. If you would like any further information or have any feedback, please contact the Research team on 02 9280 4744 or at research@carersnsw.org.au.

Care-giving dynamics and futures planning among ageing parents of adult offspring with intellectual disability

Walker, R. and Hutchinson, C. (2018), Ageing & Society, 1–16.

The increasing number of older parents ageing in tandem with their adult children with intellectual disability (ID) calls for greater research that investigates how older parents experience this extended care-giving role, including the extent to which they are engaging in futures planning. Main themes to emerge from the data were: perpetual parenting, costs and rewards and planning to plan. While some parents have started to think about future care arrangements, most appear unclear over what the future holds.

Mental Health

Experience of caregiving and coping strategies in caregivers of adolescents with an eating disorder: A comparative study

Parks, M., et al. (2018), Psychiatry Research 260: 241-247

This study aims to assess the differences in coping between caregivers of three groups: patients with an eating disorder (ED), patients with a substance use disorder, and healthy teens, and the patient and caregiver variables associated with coping and appraisal of the caregiving experience. Older ED caregivers were less likely to use avoidance. Future interventions could help ED caregivers to recognize their coping preferences and how to appropriately use these strategies when faced with illness-related stressors.

Physical health problems in people with psychosis: The issue for informal carers

Onwumere, J. et al (2018), International Journal of Social Psychiatry

The study sought to explore carers' subjective experiences of supporting a relative with psychosis and physical health problems. Five key themes were identified from the interviews that reflected ubiquity of physical health problems in psychosis, gaps in service provision for those living with mental and physical health problems, carers' role in responding to service gaps, difficult conversations and impact on carer health.

Taking parents seriously: The experiences of parents with a son or daughter in adult medium secure forensic mental health care

Finlay-Carruthers, G. et al (2018), International Journal of Mental Health Nursing

This study explored the experiences of parents with an adult son/daughter with mental illness in a medium secure mental health unit. The onset of the mental distress was narrated as overwhelming, frightening, and confusing with experiences of violence. Services were seen as invalidating, and interactions with them characterized as a battle. Poor information and involvement were a common experience.

Serious Illness / Chronic Condition

Carer Experience Supporting Someone With Dementia and Cancer: A Narrative Approach

Witham, G. et al (2017), Qualitative Health Research 28

This article examines the challenges of informal carers supporting someone with dementia and cancer. Our findings demonstrate how informal carers navigate a path through complex cancer treatments and support their relative. Carers frequently experienced multiple challenges including dealing with the stigma that is characteristic of the dementia experience and the added complexity of negotiating this within a cancer care context.

Challenges, personal growth and social support among family caregivers of terminally ill cancer patients in Southern China

Tang, Y. Qualitative Social Work

This study explores the experiences of family caregivers of terminally ill cancer patients in Shenzhen, Southern China. This study sought to describe how being the main caregiver influences family caregivers' daily lives. Three major themes were identified in their experiences: challenges, personal growth, and social support. In exploring these themes, this article offers insights into family caregivers' experiences in Southern China, particularly among family members of terminally ill cancer patients.

Implementation of a multidisciplinary psychoeducational intervention for Parkinson's disease patients and carers in the community: study protocol

Navarta-Sánchez, M. V. et al (2018), BMC Family Practice 19: 45.

Parkinson's disease progressively limits patients at different levels and as a result family members play a key role in their care. However, studies show lack of an integrative approach in Primary Care to respond to the difficulties and psychosocial changes experienced by them. This study evaluated the effects of a multidisciplinary psychoeducational intervention focusing on improving coping skills, the psychosocial adjustment to Parkinson's disease and the quality of life in patients and carers in a Primary Care setting.

Palliative Care / Bereavement

Informal Caregiver Challenges for Advanced Cancer Patients during End-of-Life Care in Johannesburg, South Africa and Distinctions Based on Place of Death

O'Neil, D. et al (2018), Journal of Pain and Symptom Management

This study aims to better understand the challenges of informal caregivers at the end-of-life for advanced cancer patients in South Africa, both at home and in inpatient facilities. Caregivers of patients dying at home reported the greatest difficulty with patients' physical symptoms; caregivers of those dying in facilities reported the greatest difficulty with emotional symptoms. Informal caregivers of patients dying at home reported challenges with practical functional care; this effect was reduced in the inpatient setting.

The experiences of caregivers providing home care for terminally ill family members at the end of life: A phenomenological study in Bahrain

Saleh, F. and O'Neill, C.S. (2018), Clinical Nursing Studies: Vol 6 No 3

This study explored the lived experience of caregivers providing home care for terminally ill family members, with the objectives of describing their experiences of caring for relatives who are terminally ill with cancer and the needs of home caregiving in Bahrain. Caregivers were not prepared for the commitment and burdens of home care when a family member is terminally ill. A reactivation of the palliative care clinic hotline service would support family caregivers. Other recommendations are discussed.

Frail & Aging

Informal care relationships and residential aged care recommendations: evidence from administrative data

Temple, J. B., et al. (2017), BMC Geriatrics 17(1): 289.

The Australian government recognises the importance of informal care to enable ageing in place. Yet, few multivariable studies have examined aspects of informal care that alter the probability of entry to residential care in Australia. Existing Australian and international studies show differing effects of informal care on entry to residential care.

For better or worse: Factors predicting outcomes of family care of older people over a one-year period. A six-country European study

Lüdecke, D. et al (2018), PLOS ONE 13

This paper describes a longitudinal study of informal care in six European countries and reports analyses that determine those factors predicting the outcomes of family care of older people over a one-year period. The support of health and social care services should be particularly targeted toward those care dyads where there is no partner or spouse acting as carer, or no extended family network that might absorb the caring role when required.

Dementia & Alzheimer's

People with Alzheimer's disease and their spouse-caregivers: differences in perceptions of sexual satisfaction?

Dow, B. and Malta, S. (2017). International Psychogeriatrics 29(2): 181-183.

As the incidence of dementia in the USA, UK and Australia increases, so does the need to understand the impact of caring on these intimate relationships, to anticipate, validate and support spousal caregivers. It is also important to understand the gender differences in these care relationships to meet the different needs of men and women caregivers. Sexual activity in later life is associated with both mental and physical health and is therefore, important to maintain, perhaps even in the context of caring for someone with dementia.

Helping Dementia Caregivers Manage Medical Problems: Benefits of an Educational Resource

Zimmerman, S., et al. (2018). American Journal of Alzheimer's Disease & Other Dementias 33(3): 176-183.

Family caregivers of people with dementia must attend to medical care needs of their relative, yet few available resources address comorbidities in dementia. Consequently, caregivers feel ill-equipped when medical concerns arise. In response, an educational resource—Alzheimer's Medical Advisor (AlzMed)—was developed in 2 forms (website and book) and evaluated. Caregivers reported significant improvements. An educational resource focusing on care of comorbid illness may benefit caregiver outcomes.

Living with a partner with dementia: a systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives

Egilstrod, B., et al. (2018), Aging & Mental Health: 1-10.

This study aimed to identify and synthesise qualitative studies on spouses' lived experiences of living with a partner with dementia. Three themes were found: Noticing changes in everyday life, Transformation to a new marital relation in everyday life, and Planning the future. Findings provide an overview of how spouses notice changes and transform their marital relationships in everyday-life, the changes that occur over time while the partner is living at home, and spouses' experiences of changes in early-stages of dementia.

Patterns of carer distress over time in mild dementia

Svendsboe, E. et al (2018), International Journal of Geriatric Psychiatry.

This study explores the level of carer reported distress in mild dementia, over a 3-year period. Being a carer to a person with mild dementia is associated with increasing distress. However, the burden of distress changes with the diagnosis, time, and situation, which highlights the dynamic nature of the caring role. Findings have important implications for health services for people diagnosed with mild dementia and their carers.

The Intention to Discuss Advance Care Planning in the Context of Alzheimer's Disease Among Korean Americans

Hong, M. et al (2018), The Gerontologist, 29.

The purpose of this study was to examine intention to discuss advance care planning (ACP) for a family member with Alzheimer's disease among Korean Americans. Guided by the theory of planned behavior and prior research, we examined the relationships between acculturation, attitudes, subjective norms, perceived control, and intention to discuss ACP for a family member with Alzheimer's disease. Educational interventions designed to address positive attitudes and subjective norms toward ACP are suggested.

Stroke / Brain Injury

Informal caregiving burden and perceived social support in an acute stroke care facility

Akosile, C. et al (2018), Health and Quality of Life Outcomes 16: 57

Providing informal caregiving in the acute in-patient and post-hospital discharge phases places enormous burden on the caregivers who often require some form of social support. There are few published studies about informal caregiving in the acute in-patient phase of individuals with stroke, in poor-resource countries. This study evaluated the prevalence of caregiving burden and its association with patient and caregiver-related variables, and level of perceived social support, in caregivers of stroke survivors in Nigeria.

Recognition & Support of Carers

An intervention that reduces stress in people who combine work with informal care: randomized controlled trial results

Boezeman, E.J et al (2018) European Journal of Public Health

This research examined whether a role-focused self-help course intervention would decrease caregiver stress and distress, and functioning problems, among people who suffer stress because they combine paid work with informal care. The intervention decreases caregiver stress and distress in people who suffer stress because they combine paid work with informal caring. The intervention (Dutch version) can be downloaded at no cost from www.amc.nl/mantelzorgstress.

Health care providers' perceptions of family caregivers' involvement in consultations within a geriatric hospital setting

Koren, D. et al (2018), Geriatric Nursing, 21.

This study explored health professionals' (HPs') experiences of interacting with family care-givers (FCs), and the strategies they employ during these interactions. Seven themes emerged. Inter-relationships between the themes were then integrated into a three-part model. This study offered insights into HPs' perspectives, experiences, and behaviours in geriatric consultations where FCs are present. Findings emphasised the need for HP training programs to improve communication and collaboration between HPs, patients, and FCs.

Carer Health & Wellbeing

Screening for caregivers at risk: Extended validation of the short version of the Burden Scale for Family Caregivers (BSFC-s) with a valid classification system for caregivers caring for an older person at home

Pendergrass, A. et al (2018), BMC Health Services Research: 229.

Informal caregivers' (CGs') subjective burden is an important aspect of the care situation because it is linked to various outcomes such as health, mortality risk, institutionalization, and caregiving style. The aims of this study were a) to examine the convergent and discriminant validity of the 10-item short version of the Burden Scale for Family Caregivers (BSFC-s) and b) to develop a valid classification system for interpreting BSFC-s scores.

Social Inclusion, Relationships & Community Participation

Community REACH: An Implementation of an Evidence-Based Caregiver Program

Czaja, S. et al (2018), The Gerontologist 58. 130-137

This paper describes and presents outcomes from Community REACH, a community implementation of the evidence-based Resources for Enhancing Alzheimer's Caregiver Health (REACH) II program. The findings indicate that evidence-based CG programs can be successfully implemented in community settings and benefit CGs of AD patients. A continued partnership between the program developers and community partners is key to implementation success.

Aboriginal Carers

A systematic review of Indigenous caregiver functioning and interventions

Hokanson, L. et al (2018), Quality of Life Research, 21.

There is a global increase in chronic, degenerative illnesses that require long-term intervention and support. The majority of support needs are met by informal family caregivers. Worldwide, Indigenous peoples face severe economic and health disadvantages that may make them even more vulnerable to the negative aspects of informal caregiving. This review aimed to synthesize the extant literature on Indigenous caregiver functioning and the interventions that are efficacious in alleviating Indigenous caregiver distress.

Young Carers

Effects of Benefit Finding, Social Support and Caregiving on Youth Adjustment in a Parental Illness Context

Pakenham, K. et al (2018), Journal of Child and Family Studies

This study aimed to test a mediational model proposal that benefit finding mediates the effects of social support and caregiving on youth adjustment in the context of parental illness. An additional aim was to further clarify the benefit finding construct in the parental illness context. This study makes an important contribution to understanding benefit finding and social support processes in the context of a chronic stressor where one of the usual sources (parents) of significant coping support is limited.

Disclaimer

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