

RESEARCH SNAPSHOT

JANUARY 2018

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 (9280 4744; research@carersnsw.org.au).

Disability

Cross-site randomized control trial of the Social ABCs caregiver-mediated intervention for toddlers with autism spectrum disorder

Brian, J. A., et al. (2017). Autism Research 10(10): 1700-1711.

This study evaluated the efficacy of the Social ABCs parent-mediated intervention for toddlers with suspected or confirmed autism spectrum disorder (ASD). The Social ABCs is a relatively low-resource, efficacious intervention, with potential to be a cost-effective means of intervening at the first signs of possible ASD.

Social and Instrumental Interaction Between Parents and Their Toddlers With Autism: A Qualitative Analysis

Schertz, H. H., et al. Journal of Early Intervention 0(0)

Investigated parent-toddler interactions in toddler's with autism, and how the nature of one partner's actions influenced the other. Themes identified were: the partner as instrument, attempted but missed social connections, and congruent social engagement. Findings suggest that actively supporting parents to interact with their toddlers socially, rather than prescriptively or instrumentally, may be a potent intervention.

Mental Health

A Longitudinal Study of Health Care Resources, Family Support, and Mental Health Outcomes Among Suicidal Adolescents

LeCloux, M., et al. Analyses of Social Issues and Public Policy

This study examined the longitudinal relationships between four resources (public insurance, primary care services, school-based mental health treatment, and family support) and depression and suicidality in a nationally representative sample of suicidal adolescents. Intervention points for future policy are discussed.

Experiences of Family Stigma among Mothers of Adult Children with Mental Illness in South Korea

Hyun, M.-S., et al. (2017). Issues in Mental Health Nursing 38(10): 845-851.

Explores the lived experiences of family stigma among mothers of mentally ill children in South Korea. Six themes emerged; being ashamed, feeling of being ignored, isolating oneself from social relationships, becoming a mentally sick person, living like a guilty person, and becoming part of the socially weak. Findings contribute to our understanding of the stigma and will aid the development of culturally appropriate strategies.

Psychological Correlates of Burden Among Jordanian Caregivers of Patients With Serious Mental Illness

Ghannam, B. M., et al. (2017). Perspectives in Psychiatric Care 53(4): 299-306.

Examined prediction power of personality traits, expressed emotion, and coping strategies on caregiver burden. Burden had a significant negative relationship with coping and significant positive relationship with personality dysfunction. Emotional expression, coping, and personality were found to be significant predictors of burden. Findings suggest mental health professionals need to address caregivers in their plans of care.

Drug / Alcohol Dependency

Efficacy of a Web-based Intervention for Concerned Spouses of Service Members and Veterans with Alcohol Misuse

Osilla, K. C., et al. Journal of Marital and Family Therapy

Concerned partners (CPs) of service members and veterans who misuse alcohol face help-seeking barriers and mental health problems. This study evaluated the efficacy of Partners Connect, a web-based intervention to address military CPs' mental health and communication. The program reported significant reductions in anxiety and increases in social support. Partners Connect appears to fill a need for families who face help-seeking barriers and provides an alternative to traditional care for those who may not otherwise seek help.

Serious Illness / Chronic Condition

Do not forget the parents—Parents' concerns during transition to adult care for adolescents with congenital heart disease

Bratt, E. L., et al. Child: Care, Health and Development

This study explored parents' expectations and needs during their adolescent's transition to adult care in adolescents with congenital heart disease. Being prepared and informed about the upcoming transition process was essential. Parents underlined the importance of being involved in the transition planning for gradually handing over responsibility to the adolescent. They also considered establishing contact with the adult healthcare team before transfer as important.

Depressive symptoms among older caregivers raising children impacted by HIV/AIDS in the Omusati Region of Namibia

Kalomo, E., et al. (2017). Health Care for Women International: 1-17.

This study explores the role of financial strain, raising a HIV-infected and/or impacted child, and caregiver knowledge on the depressive symptoms of 89-older caregivers raising HIV/AIDS-orphans in Namibia, Africa. In this study, we found elevated levels of depressive symptoms among this population. A significant negative association between caring for an HIV-infected orphan and depression was shown. Our work suggests the need for economic assistance programs and psychosocial interventions for older caregivers.

The experiences of patients with advanced cancer and caregivers presenting to Emergency Departments: A qualitative study

Philip, J., et al. Palliative Medicine 0(0)

This study explored the experiences and perceptions of Emergency Departments held by patients with advanced cancer and their informal caregivers. The results suggest that relatively simple changes of regular communication updates and early symptom relief would improve patient experience of Emergency Department care. However, since an Emergency Department presentation is frequently serving as a default to access medical care, a significant re-orientation of the health care system is required to meet patient needs.

Aging and HIV-Related Caregiving in Sub-Saharan Africa: A Social Ecological Approach

Small, J., et al. (2017). The Gerontologist: gnx159-gnx159.

This study reviewed the literature on older adults (OAs) who are caring for persons living with HIV/AIDS in sub-Saharan Africa (SSA). Factors promoting caregiver resilience included spirituality, bidirectional (reciprocal) caregiving, and collective coping strategies. The creation of a theoretical model of caregiving which focuses more broadly on the sociocultural context of caregiving could lead to new ways of developing interventions in low-resources communities.

Depressive symptoms among older caregivers raising children impacted by HIV/AIDS in the Omusati Region of Namibia

Kalomo, E., et al. (2017). Health Care for Women International 38(12): 1327-1343.

This study explores the role of financial strain, raising a HIV-infected and/or impacted child, and caregiver knowledge on the depressive symptoms of 89-older caregivers raising HIV/AIDS-orphans in Namibia, Africa. Findings indicate elevated levels of depressive symptoms among this population. Our work suggests the need for economic assistance programs and psychosocial interventions for older caregivers.

Siblings' caring roles in families with a child with epilepsy

Webster, M. Sociology of Health & Illness

Despite large amounts of care for chronic conditions being provided within the family, information regarding the extent to which siblings contribute to informal care practices in families where a child has a chronic condition is limited. This article illustrates siblings' significant contribution to caring for their brother or sister and further develops the alert assistant concept. Two additional distinct caring roles that the siblings took on are also outlined – the substitute parent and parenting assistant roles.

Palliative Care / Bereavement

Caregiver quality of life in advanced cancer: Qualitative results from a trial of early palliative care

McDonald, J., et al. Palliative Medicine

This study considers quality of life (QoL) of caregivers and differences between those who did or did not receive early palliative care intervention. Five themes related to the core category ('living in the patient's world') were: 'burden of illness and caregiving', 'assuming the caregiver role', 'renegotiating relationships', 'confronting mortality' and 'maintaining resilience'. QoL is influenced by interaction with the patient and should be measured with questionnaires related to confronting mortality and professional supports.

Home palliative care works: but how? A meta-ethnography of the experiences of patients and family caregivers

Sarmiento, V. P., et al. (2017). BMJ Supportive & Palliative Care 7(4): 00.

The study explored patients and family caregivers' experiences with home palliative care services. 2 overarching components of home palliative care were identified: presence (24/7 availability and home visits) and competence (effective symptom control and skilful communication), contributing to meet the core need for security. Home palliative care teams improve patients and caregivers experience of security when facing life-limiting illnesses at home, by providing competent care and being present.

Hospice Family Caregiver Involvement in Care Plan Meetings: A Mixed-Methods Randomized Controlled Trial

Oliver, D. P., et al. (2017). American Journal of Hospice and Palliative Medicine® 34(9): 849-859.

This study considered an intervention to improve caregiver's perception of pain management and patient's pain. The hospice philosophy is supportive of caregiver involvement in care planning, and technology makes this feasible; the intervention needs modification to become translational. Caregiver education and emotional support should occur outside the meeting, and a strong leader should facilitate the meeting to control efficiency. Finally, the intervention may benefit caregivers of patients with cancer more than others.

How continuity of care is experienced within the context of integrated palliative care: A qualitative study with patients and family caregivers in five European countries

Eerden, M. d. H.-v. d., et al. (2017). Palliative Medicine 31(10): 946-955.

This study examined how relational, informational and management continuity of care are experienced by patients with advanced diseases and their family caregivers. Patients and family caregivers most likely experience continuity of care by having a small number of trusted health care professionals who are available, provide multidisciplinary care and regularly transfer information to all health care professionals involved. Optimizing continuity of care requires further integration of integrated palliative care initiatives.

A Randomized Controlled Trial of Strategies to Improve Family Members' Preparedness for Surrogate Decision-Making

Green, M. J., et al. American Journal of Hospice and Palliative Medicine® 0(0)

This study evaluated 2 strategies for preparing family members for surrogate decision-making. The strategies tested whether: (1) comprehensive online advance care planning (ACP) is superior to basic ACP, and (2) having patients engage in ACP together with family members is superior to ACP done by patients alone. The disconnection between confidence and performance raises questions about how to prepare family members to be surrogate decision-makers.

Rural end-of-life care from the experiences and perspectives of patients and family caregivers: A systematic literature review

Rainsford, S., et al. (2017). Palliative Medicine 31(10): 895-912.

This study describes end-of-life (EoL) care experiences and perspectives of rural patients and their family caregivers, identifies facilitators and barriers to receiving EoL care in rural/remote settings and describes the influence of rural place and culture on EoL care experiences. The greatest needs were informational (developed countries) and medications (developing countries). Influence of rural location included distances, inaccessibility to EoL care services, strong community support and importance of home and 'country'.

Ageing

Formal and informal care for community-dwelling frail elderly people over time: A comparison of integrated and usual care in the Netherlands

Janse, B., et al. Health & Social Care in the Community

This study examined how an integrated care intervention for community-dwelling frail elderly people affects the amount and type of formal and informal care over 12 months as compared to usual care. Results suggest that integrated care does not necessarily change the contribution of formal or informal care, but changes the interaction between formal (personal care) and informal (instrumental) activities.

High perceived caregiver burden for relatives of patients following hip fracture surgery

Ariza-Vega, P., et al. (2017). Disability and Rehabilitation: 1-8.

This study aims to determine the profile of informal caregivers, the evolution of the caregiver burden, and the influencing factors of caregiver burden at 1-year after hip fracture surgery. The main caregiver is predominantly female and is most often the daughter of the patient. Caregivers of older patients, those with a low pre-fracture functional level, and of those who suffered post-operative complications, should receive more attention prior to hospital discharge and receive more assistance at home to reduce caregiver burden.

Perspectives on the Delirium Experience and Its Burden: Common Themes Among Older Patients, Their Family Caregivers, and Nurses

Schmitt, E. M., et al. (2017). The Gerontologist

This study describes common delirium burdens from the perspectives of patients, family caregivers, and nurses. Three common themes were identified: Symptom Burden; Emotional Burden; and Situational Burden. Findings advance the understanding of common burdens of the delirium experience for all groups and offer structure for instrument development and distinct interventions to address the burden of delirium as an individual or group experience.

Dementia

Caregiver Experiences Across Three Neurodegenerative Diseases: Alzheimer's, Parkinson's, and Parkinson's With Dementia

Roland, K. P. and N. L. Chappell, Journal of Aging and Health

This article asks whether distinct caregiver experiences of Alzheimer's disease (AD), Parkinson's disease (PD), and Parkinson's disease with dementia (PDD) spouses are accounted for by disease diagnosis or by a unique combination of symptoms, demands, support, and quality of life (QOL) across disease groups. Four clusters cut across disease diagnosis: 'Succeeding,' 'Coping,' 'Getting by with support,' and 'Struggling.' This study supports going beyond disease diagnosis when examining caregiver experiences.

Modern technology to support carers of care recipients with dementia or functional mental illness: promising progress, but a long road ahead

Lautenschlager, N. T., et al. (2017). International Psychogeriatrics 29(12): 1933-1935.

This study explores effective strategies to support carers and how the use of technological innovations could contribute to better supporting carers. Telehealth approaches via videoconferences have the potential to better support carers who live in rural or remote regions (O'Connell et al.) or who cannot attend face-to-face support programs for other reasons such as inability to leave the care recipient alone at home, being a multiple carer or having a disability themselves.

A Needs-led Framework for Understanding the Impact of Caring for a Family Member With Dementia

Pini, S., et al. (2017). The Gerontologist

This study aims to develop and present a needs-led framework for understanding how providing care impacts on carers' fulfilment of needs for carers for a family member with dementia. The findings revealed needs which echo those from other research areas, with relational needs emerging as particularly central. The needs-led approach offers a perspective that is able to capture both stresses and positive aspects of caregiving.

Positive Aspects of Caregiving and Caregiver Burden: A Study of Caregivers of Patients With Dementia

Abdollahpour, I., et al. Journal of Geriatric Psychiatry and Neurology 0(0)

This study investigated the association of caregiver burden and positive aspects of caring (PAC). Results indicated a negative significant association of caregiver burden with PAC, reinforcing the need for interventional and/or educational programs aimed at decreasing the overall imposed burden. This can play an important role in improving caregivers' general health and quality of life.

Randomized Controlled Trial of Inner Resources Meditation for Family Dementia Caregivers

Waelde, L. C., et al. (2017). Journal of Clinical Psychology 73(12): 1629-1641.

This study examined the comparative effectiveness of 2 interventions for improving diurnal cortisol slope and life satisfaction and reducing stress symptoms among older female dementia family caregivers. Results indicate that mindfulness meditation and mantra has promise as a feasible and effective caregiver intervention for quality of life and physiological responding to stress.

Stress-buffering Effect of Coping Strategies on Interrole Conflict among Family Caregivers of People with Dementia

Morimoto, H., et al. (2017). Clinical Gerontologist: 1-13.

This study examines the stress-buffering effect of coping strategies on the adverse effects of interrole conflict on the mental health of employed family caregivers, and clarifies the moderating role of attentional control. Greater use of formal support seeking weakens the adverse effects of strain- and behavior-based caregiving interfering with work (CIW) on psychological strain in people with high attentional control. Attentional control is a key factor in the stress-buffering effect of formal support seeking on strain- and behavior-based CIW.

What behavioral and psychological symptoms of dementia affect caregiver burnout?

Hiyoshi-Taniguchi, K., et al. (2017). Clinical Gerontologist

This study examines the connection between behavioral and psychological symptoms of dementia (BPSD) and the burnout of caregivers caring for elders living at home with such symptoms in Japan. Findings indicate advance diagnosis of BPSD symptoms should be helpful to support nurses and caregivers of dementia patients. Particular support should be considered for caregivers and nurses of patients expressing aggression, irritability, abnormal motor behaviour, and hallucination.

The Impact of the Physical Home Environment for Family Carers of People with Dementia: A qualitative study – Journal of Housing For the Elderly

Soilemezi, Dia; Kallitsis, Phevos; Drahota, Amy et al. Journal of Housing For the Elderly

This study considered perceptions of family carers of people with dementia on home environmental aspects and strategies. Three themes emerged: aspects of architectural and interior environment, environmental strategies encouraging independence and comfort at home, and carers' scepticism, timing, costs, property characteristics and mistrust to services. Carers improvised solutions via trial and error and need further education on strategies to create an enabling and comfortable home environment.

An Assessment of the Burden on Polish Caregivers of Patients With Dementia: A Preliminary Study

Kowalska, J., et al. (2017). American Journal of Alzheimer's Disease & Other Dementiasr 32(8): 509-515.

This study assessed the level of burden of caregivers of persons with dementia. In the study group, 93% could rely on help in caring for the patient, provided mainly by the family. Most caregivers demonstrated a medium level of burden. A significant correlation was found between the level of caregiver burden and caregiving frequency. Findings suggest many factors influence the caregivers' burden. It appears necessary to take into consideration the cultural, religious, and economic distinctiveness of the country in question.

Stroke / Brain Injury

“I Don’t Believe in Leading a Life of My Own, I Lead His Life”: A Qualitative Investigation of Difficulties Experienced by Informal Caregivers of Stroke Survivors Experiencing Depressive and Anxious Symptoms

Woodford, J., et al. (2017). *Clinical Gerontologist*: 1-15.

This study aims to understand the specific difficulties experienced by caregivers of stroke survivors, experiencing elevated symptoms of anxiety and depression. Analysis revealed three main themes: Difficulties adapting to the caring role; Uncertainty; and Lack of support. Caregivers experienced significant difficulties adapting to changes and losses associated with becoming a caregiver. These difficulties persisted into the long-term and were coupled with feelings of hopelessness and worry.

Recognition & Support of Carers

Building Better Caregivers: A Pragmatic 12-Month Trial of a Community-Based Workshop for Caregivers of Cognitively Impaired Adults

Lorig, K., et al. *Journal of Applied Gerontology*

Building Better Caregivers (BBC), a community 6-week, peer-led intervention, targets family caregivers of those with cognitive impairments. Caregiver strain and depression improved significantly. All secondary outcomes except exercise and caregiver health care utilization improved significantly. Baseline and 6-month improvements in self-efficacy were associated with improvements in caregiver strain and depression. In this pilot study, BBC appears to assist caregivers while reducing care partner health care utilization.

Strapped for Time or Stressed Out? Predictors of Work Interruption and Unmet Need for Workplace Support Among Informal Elder Caregivers

Andersson, M. A., et al. *Journal of Aging and Health* 0(0)

This study evaluates whether strong associations between unmet need and work interruption observed among informal elder caregivers are explained by caregiver personal characteristics, caregiving situations, or diminished caregiver well-being. Unmet need was about twice as common among those experiencing mild or severe interruption relative to those who did not interrupt work. Needs-related work interruptions may arise by other workplace processes, such as organizational culture, that should be researched further.

Carer Health & Wellbeing

Expressed emotion in couples facing breast cancer in women is associated with psychological distress in the first year after surgery

Favez, N., et al. *Journal of Health Psychology* 0(0)

The aim of this study was to assess the links between partners' and women's expressed emotion with the distress of one another during the first year after surgery for breast cancer in women. Analyses showed that partners' expressed emotion is associated with heightened psychological distress in women during the first year after surgery, even after medical data were controlled for.

Operation family caregiver: Problem-solving training for military caregivers in a community setting

Easom, L. R., et al. *Journal of Clinical Psychology*: n/a-n/a.

This study describes the outcomes of an evidence-based support program, Operation Family Caregiver, to gain an understanding of how a tailored, problem-solving training could assist military caregivers, who provide care and assistance to those injured, ill, or disabled as a result of war. This program may be beneficial to caregiving families of military service and veterans living with posttraumatic stress, traumatic brain injury, and/or a physical disability.

Social Inclusion, Relationships & Community Participation

Attending school after treatment for a brain tumor: Experiences of children and key figures

Vancloster, S., et al. Journal of Health Psychology

This study explored the experiences of childhood brain tumour survivors and their parents following school re-entry. Four main themes emerged: "school performance," "psychosocial well-being," "support and approach," and "communication and collaboration." Children were pleased to return to school despite confrontation with adverse outcomes. Parents, teachers, and healthcare providers identified current and future concerns and challenges, as well as opportunities for academic and personal development.

Caregiving Spouses and the Experience of Involuntary Separation

Glasier, W. C. and K. J. Arbeau (2017). The Gerontologist: gn163-gn163.

This study aimed to explore the lifeworld experience of caregiving spouses during involuntary separation, including factors influencing well-being. Participants experienced involuntary separation as an overwhelming burden marked by ongoing losses, from connections with spouses and social supports to shifts in identity and financial security. Greater understanding of their unique needs and experiences may help individuals cope in practical ways with their shifting situation and highlights the value of meaning-focused support.

Carers & Gender

Fathers' experiences of their child's life-limiting condition: An attachment narrative perspective

Bailey-Pearce, O., et al. Clinical Child Psychology and Psychiatry 0(0)

This study considers the experiences of fathers regarding their child's life-limiting illness. The dominant themes were found to be 'experience of the diagnosis', 'living with the illness', 'struggling with emotions' and 'relationship with staff'. The findings also suggested that the experience for the fathers stressed, and in some cases disrupted, their attachment coping strategies. All fathers told stories of trying to get it right for their children and family.

Fathers of adults who have a learning disability: Roles, needs and concerns

Davys, D., et al. (2017). British Journal of Learning Disabilities 45(4): 266-273.

This study asked fathers of adults who have a learning disability about their roles, needs and concerns. Although mothers are often the main carers for adults with a learning disability, fathers can make a significant contribution. The findings support previous studies regarding paternal response to learning disability and varied impact upon men's lives. Ongoing concerns incorporate the future and ambivalent relationships with service providers, which could have a negative impact upon the individual who has a learning disability.

Young Carers

Caregiving Load and Respite Service Use: A Comparison between Older Caregivers and Younger Caregivers

Shi, J., et al. (2017). Journal of Gerontological Social Work: 1-14.

This study aims to explore differences in predictors of respite care use between older and younger caregivers, and associations between caregiving load and respite care use. Caregiving load comprised of number of care recipients, weekly hours in caregiving, and caregiving duration. Variables with a significant association with respite care for older caregivers were female gender, income, and health insurance. For younger caregivers, respite care use associations were with ethnicity, caregiving relationship, education, and substitute help.

Former Carers

The Impact of Hospice Patient Disease Type and Length of Stay on Caregiver Utilization of Grief Counseling: A 10-Year Retrospective Study

Palmer, W. W. and F. K. Yuen (2017). American Journal of Hospice and Palliative Medicine® 34(9): 880-886.

This investigation explored the relationship between hospice patient disease type, length of stay (LOS) in hospice, and caregiver utilization of grief counseling in bereavement. For caregivers who utilized only 1 counseling session, the associated patient median LOS was 21.5 days. For caregivers who utilized 5 or more counseling sessions, the associated patient median LOS dropped to 12 days, suggesting an inverted relationship between hospice patient LOS and the duration of counseling in bereavement.

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