

RESEARCH SNAPSHOT

MAY 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

Applying Andersen's Model to Explain Service Use and Quality of Life Among Australian Caregivers of Children with Autism Spectrum Disorder

Willett, M., Dorstyn, D., et al. (2018). Journal of Developmental and Physical Disabilities.

This study aimed to understand patterns of health service utilization, in order to better tailor current services to meet caregivers' quality of life (QOL) needs. Personal barriers to health care utilization exist for parents of children with ASD which impact their decision to access help. There is, however, a need for further research to expand Andersen's model by examining subjective and objective QOL indicators applicable to the caregiver cohort.

Mental health care needs and preferences for mothers of children with a disability

Gilson, K.-M., Davis, E., et al. (2018). Child: Care, Health and Development.

This article describes the mental health care needs and preferences for support of mothers of children and young people with a disability. Although mental health problems were common and mothers perceived the need for professional help, several barriers prevented mothers from accessing help. The study suggests improving mothers' knowledge of when and where to seek help may encourage their access to support, and recommends more accessible treatment to mothers, given the high care demands placed upon them.

Mental Health Interventions for Parent Carers of Children with Autistic Spectrum Disorder: Practice Guidelines from a Critical Interpretive Synthesis (CIS) Systematic Review

Catalano, D., Holloway, L., et al. (2018). International Journal of Environmental Research and Public Health.

This study identifies key qualities of interventions supporting the mental health of parent carers and proposes practitioner-parent carer support guidelines. Findings suggest practitioner guidelines to support the mental health and wellbeing of parent carers should include addressing the parent's self-perspective taking and skill for real time problem-solving.

Mental Health

Hours of Care and Caring Tasks Performed by Australian Carers of Adults with Mental Illness: Results from an Online Survey

Hielscher, E., Diminic, S., et al. (2018). Community Mental Health Journal.

This article provides a detailed profile of the hours of care Australian mental health carers provide for different types of caring tasks. Mental health carers reported providing on average 37.2 h of care/week to their main care recipient. Carers highlighted that care time fluctuates with the undulating nature of mental illness, and many noted additional hours devoted to being 'on call' in case of emergency. Government services need to match the undulating nature of the illness by providing more flexible support options for mental health carers.

A web-based intervention for carers of individuals with anorexia nervosa (We Can): Trial protocol of a randomised controlled trial investigating the effectiveness of different levels of support

Spencer, L., Schmidt-Hantke, J., et al. (2018). Internet Interventions.

Anorexia nervosa (AN) is a mental disorder associated with substantial caregiver burden. Carers of individuals with AN report high levels of distress and self-blame, and insufficient knowledge to help their loved ones. However, carers can have a very important role to play in aiding recovery from AN, and are often highly motivated to assist in the treatment process. This study investigates the effectiveness of We Can, a web-based intervention for carers for people with AN, delivered with different intensities of support.

Barriers to Family Caregivers' Coping With Patients With Severe Mental Illness in Iran

Ebrahimi, H., Seyedfatemi, N., et al. (2018). Qualitative Health Research.

This study explored barriers impeding family caregivers' ability to cope with their relatives diagnosed with severe mental illness (defined here as schizophrenia, schizoaffective disorders, and bipolar affective disorders). Findings consisted of four major categories: the patient's isolation from everyday life, incomplete recovery, lack of support by the mental health care system, and stigmatization. Findings highlight the necessity of providing support for caregivers by the mental health care delivery service system.

Living with someone with an eating disorder: factors affecting the caregivers' burden

Stefanini, M.C., Troiani, M.R., et al. (2018). Eating and Weight Disorders – Studies on Anorexia, Bulimia and Obesity.

This study focused on carers of subjects suffering from eating disorders (ED), and considered the characteristics that expose them to high levels of stress, anxiety, depression and expressed emotion. A personal history of ED, being the primary carer, and caring for a person with a diagnosis of anorexia nervosa are the characteristics that contribute most to aggravate carers' burden. Our findings may help doctors to provide effective support to caregivers and eventually improve the treatment of subjects with ED.

Understanding the experience of “burnout” in first-episode psychosis carers

Onwumere, J., Sirykaite, S., et al. (2018). Comprehensive Psychiatry.

The study investigated reports of burnout and its relationship with beliefs about caregiving and wellbeing in early psychosis carers. Carers reported exhaustion, feeling inadequate and expressing negativity towards the relative they care for, factors which are closely associated with carers' overall negative appraisals of caregiving. The results underscore the importance of developing targeted interventions during the early phase, designed to reduce the development and entrenchment of burnout responses in carers.

Serious Illness / Chronic Condition

Associations between the psychological health of patients and carers in advanced COPD

Mi, E., Ewing, G., et al. (2017). International Journal of COPD.

This study investigated the link between patient and carer anxiety and depression in patients with COPD and their informal carers. Results suggest that symptoms of anxiety and depression in COPD patients and carers are significantly associated. Given their high prevalence, considerable impact on mortality, impact on quality of life and health care use, and associations with each other, screening for and addressing patient and carer anxiety and depression in advanced COPD is recommended.

Family and Other Caregivers

Gately, M., Ladin, K., et al. (2018). Chronic Illness Care: Principles and Practice. Springer International Publishing.

It could be said that “it takes a village” to manage a chronic condition. Caregivers’ own needs must be met, lest they become at risk for developing poor outcomes themselves. Supporting caregivers also helps them maintain caregiving roles, which are often valued by both caregiver and care recipient. This chapter describes the effects on caregivers who are supporting individuals living with a chronic condition. Information about assessment and intervention, opportunities for further research, and populations of concern are highlighted.

Qualitative study of challenges of caring for a person with heart failure

Bangerter, L.R., Griffin, J.M., et al. (2018). Geriatric Nursing.

Heart failure (HF) is a chronic health condition that causes significant morbidity among older adults, many of whom receive support and care from an informal caregiver. An in-depth understanding of these challenges is necessary to develop services, resources, and interventions for HF caregivers. The goal of this study was to qualitatively ascertain the most significant challenges facing HF caregivers. The findings can be used to inform interventions and support services for HF caregivers.

Quality of life and level of burden in primary caregivers of patients with epilepsy: Effect of neuropsychiatric comorbidity

Gurierrez-Angel, A.M., Martinez-Juarez, I.E., et al. (2018). Epilepsy & Behaviour.

This study aimed to describe quality of life (QOL) and level of burden (LB) in carers of people with epilepsy, and to determine if LB and QOL were different between carers of patients with and without neuropsychiatric comorbidity. Aggressive behavior was most clearly associated with lower QOL and higher LB. Longer duration of epilepsy was related to higher LB and lower QOL. More years of education of the carer were associated with better QOL. There was no significant correlation between seizure control and QOL or LB.

Relevance of sleep quality on caregiver burden in Parkinson’s disease

Bartolomei, L., Pastore, A., et al. (2018). Neurological Sciences.

This study examined the relationship of patients’ sleep quality and depression on burden, mood, quality of life, and quality of sleep of their caregivers, in people with Parkinson’s disease (PD). This study underscores the presence of a significant relationship between patient and caregiver quality of life. Interestingly, sleep quality and depression rather than motor disability, best predicted caregivers’ well-being.

Palliative Care / Bereavement

A framework for complexity in palliative care: A qualitative study with patients, family carers and professionals

Pask, S., Pinto, C., et al. (2018). Palliative Medicine.

This study explored palliative care stakeholders’ views on what makes a patient more or less complex and insights on capturing complexity at patient-level. Participants’ understanding of complexity extended far beyond the commonly used physical, psychological, social and spiritual domains. Findings were categorized into the microsystem, chronosystem, mesosystem, exosystem and macrosystem. Stakeholders found it acceptable to capture complexity at the patient-level, with perceived benefits of improving resource allocation.

Carer experience of end-of-life service provision: a social network analysis

Leonard, R., Horsfall, D., et al. (2018). BMJ Supportive Palliative Care.

This study aims to identify the position of formal service providers in the networks of those providing end-of-life care in the home from the perspective of the informal network. The results supported the Circles of Care model and mirror the perspective of formal service providers identified in previous research. The research raises questions about how formal and informal networks might be better integrated to increase their effectiveness for supporting in-home care.

Differential Family Experience of Palliative Sedation Therapy in Specialized Palliative or Critical Care Units

Shen, H.S., Chen, S.Y., et al. (2018). Journal of Pain and Symptom Management.

This study examines and compares family concerns about palliative sedation therapy (PST) use and its effect on the grief suffered by terminally ill patients' families in palliative care units (PCUs) or intensive care units (ICUs). Family experiences with the use of PST in terminally ill patients varied in different settings. Supportive care should address family concerns about PST use, and regular attention should be paid to the grief of individuals at higher risk.

Randomised clinical trial of an early palliative care intervention (SUPPORT) for patients with idiopathic pulmonary fibrosis (IPF) and their caregivers: protocol and key design considerations

Lindell, K.O., Nouraei, M., et al. (2018). BMJ Open Respiratory Research.

This study tests the efficacy of SUPPORT intervention for idiopathic pulmonary fibrosis (IPF) patients and their families. The trial will evaluate whether the intervention decreases stress, improves symptom burden, quality of life, preparedness and advance care planning for patients and caregivers, quality of dying and death for caregivers if the patient dies during the course of the study, and assess the impact of primary palliative care on healthcare resource use near the EOL.

Aged & Dementia

Caregiver Reactions to Aggressive Behaviors in Persons With Dementia in a Diverse, Community-Dwelling Sample

Hansen, B.R., Hodgson, N.A., et al. (2018). Journal of Applied Gerontology.

This study describes caregiver challenges and confidence managing of three aggressive behavior types in persons with dementia: verbal aggression, destroying property, and threatening to hurt others. Aggressive behaviors challenge caregivers, with reactions varying by behavior type and race/ethnicity. Cultural and contextual factors suggest the need to tailor interventions, especially skill-building interventions that increase confidence managing aggressive behaviors while decreasing upset.

Cognitive Behavioral Therapy for Depression, Anxiety, and Stress in Caregivers of Dementia Patients: A Systematic Review and Meta-Analysis

Hopkinson, M.D., Reavell, J., et al. (2018). The Gerontologist.

This study evaluated changes in dementia caregivers' depression, anxiety, and stress following cognitive behavior therapy (CBT), and assessed quality of life, intervention adherence/satisfaction and therapy effectiveness using different formats, frequencies, and delivery methods. Depression and stress were significantly reduced after CBT, while anxiety was not. Group CBT provides small but significant benefits to caregivers' depression and stress. Therapy may be improved by limiting to group formats and eight sessions.

Feasibility of applying the psychosocial intervention STRategies for Relatives to family caregivers of patients with dementia: a case report

Masami, K., Toshiaki, N., et al. (2018). Psychogeriatrics.

The purpose of this study was to investigate the feasibility of applying STRategies for Relatives (START), a psychosocial intervention program developed in the UK to improve caregivers' moods and quality of life, to Japanese family caregivers of patients with dementia. The investigation found that the Japanese version of START is a feasible option. This result supports the wider application of START in Japan and the development and implementation of other systems that can provide similar services for other caregivers.

Parental health limitations, caregiving and loneliness among women with widowed parents: longitudinal evidence from France

van den Broek, T. & Grundy, E. (2018). European Journal of Ageing.

This article investigates how daughters' feelings of loneliness are impacted when widowed parents develop health limitations, and when daughters take on personal care tasks in response. Findings suggest that more attention to the psychosocial impact of parental health limitations—net of actual caregiving—on adult children's lives is warranted.

Psychopathological Symptoms in Caregivers of Demented and Nondemented Patients

Vázquez, F., Torres, A., et al. (2018). Caregiving and Home Care. InTech.

This book examines role of home care services in the management of chronic diseases. The first section explains the concept of caregiving and care at home, the responsibilities of caregivers at home and those of caregivers of people who have health problems that occur during different periods of life. The second section discusses the problems of caregivers. This book is presented to all health professionals working in the field of health services as well as health politics professionals and students trained in these areas.

Reliability, validity and relevance of needs assessment instruments for informal dementia caregivers: a psychometric systematic review protocol

Kipfer, S., Eicher, M., et al. (2018). JBI Database of Systematic Reviews and Implementation Reports.

The review aims to identify needs assessment instruments for dementia caregivers, which are reliable and valid in measuring their needs, and relevant for clinical practice, research and informal caregivers. More specifically, it presents an overview and evaluation of the available needs assessment instruments, including: their psychometrics (reliability and validity), and their relevance according to the instrument characteristics (their purpose, application method, administration burden, number of items and domain structure).

Stroke / Brain Injury

Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services – A systematic review and meta-ethnography

Pindus, D.M., Mullis, R., et al. (2018). PLOS ONE.

This study aims to describe and explain stroke survivors and informal caregivers' experiences of primary care and community healthcare services in order to offer potential solutions for how negative experiences could be addressed by healthcare services. Stroke survivors and caregivers feel abandoned because they have become marginalised by services and they do not have the knowledge or skills to re-engage. This can be addressed by increasing stroke specific health literacy by targeted and timely information provision.

Recognition & Support of Carers

Staff experiences of double-duty caring: At home and at work

Brindley, C. (2017). Nursing Management.

Many healthcare, social care and voluntary agency employees are carers at work and at home, a phenomenon referred to as double-duty caregiving. This article provides a deeper, richer picture of the experience of double-duty caring, revealing the sacrifices associated with being a carer at home while employed in a healthcare system, and the paradoxical effects of holding a position in both worlds simultaneously.

Carer Health & Wellbeing

Systematic review of caregiver burden in spouses and partners providing informal care to wounded, injured or sick (WIS) military personnel

Thandi, G., Harden, L., et al. (2018). Journal of the Royal Army Medical Corps.

This review aims to identify burden among spouses/partners caring for wounded, injured or sick military personnel and the factors associated with caregiver burden. Caring for an injured or ill military spouse or partner is a difficult task, compounded by the complexity of dealing with potentially both their physical and mental health problems. However, research has also identified some positive aspects of caring that can strengthen intimate relationships.

Social Inclusion, Relationships & Community Participation

What Does the Implementation of Peer Care Training in a U.K. Prison Reveal About Prisoner Engagement in Peer Caregiving?

Stewart, W. (2018). Journal of Forensic Nursing.

A qualitative study was implemented to design, deliver, and evaluate a peer care training intervention within a U.K. prison for ageing and chronically ill prisoners and their peers. The perceptions of six prisoner peer caregivers are represented in this article. The social processes underpinning prisoner peer caregiving are discussed, including individual and organizational impediments to the fulfillment of their role. Practice theory, social learning theory, and criminological sensitivities were used as theoretical lenses to analyze the findings.

Spirituality & Religion

Spirituality among family caregivers in palliative care: an integrative literature review

Lalani, N., Duggleby, W., et al. (2018). International Journal of Palliative Nursing.

This study aims to evaluate and synthesise studies on spirituality among family caregivers in palliative care. Five themes were identified: a close and meaningful connection, spirituality as a way of coping, spiritual needs and expressions among family caregivers, spirituality to transcend fears, and spirituality in family caregivers' decision-making. Nurses are encouraged to explore the spirituality and spiritual experiences of family caregivers to support their spiritual wellbeing while caring for their terminally ill family members.

Carers & Gender

Portrayals of caring masculinities in fiction film: The male caregiver in still mine, intouchables and Nebraska

Araüna, N., Willem, C., et al. (2018). Masculinities and Social Change. Doi not working?

This article analyzes the male caregiving characters Driss in *Intouchables* (2011), Craig in *Still Mine* (2012) and David in *Nebraska* (2013) in terms of hegemonic masculinity and its variations. Our findings show that despite the tension men experience between giving in to and challenging patriarchal privilege of a carefree life, strategies such as humour, complicity, outdoor action and a general concern for the dignity of the care-receiver can be identified as some of these features of caring masculinities and open new spaces for defining care as a gender neutral activity.

The development of an online intervention (Care Assist) to support male caregivers of women with breast cancer: a protocol for a mixed methods study

Levesque, J.V., Gerges, M., et al. (2018). BMJ Open.

This study will examine the experiences of male caregivers of women with breast cancer, looking at six key areas. Data analysis will include examination of differences in psychological outcomes and needs based on demographic variables, and mediation analysis to explore whether self-efficacy mediates the relationship between challenges, unmet needs and distress.

Young Carers

Childhood Caregiving Roles, Perceptions of Benefits, and Future Caregiving Intentions Among Typically Developing Adult Siblings of Individuals with Autism Spectrum Disorder

Nuttall, A.K., Coberly, B., et al. (2018). Journal of Autism and Developmental Disorders.

Typically developing siblings (TDS) of individuals with Autism Spectrum Disorder (ASD) frequently serve as caregivers during childhood, known as parentification, and primary caregivers for siblings in adulthood. This study evaluated the mechanisms linking these roles, considered current perceptions of benefits associated with ASD and with engaging in parentification, and intention to provide future caregiving. Results indicate that parent-focused parentification is common and associated with fewer perceived benefits of caregiving.

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