

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 (02 9280 4744; research@carersnsw.org.au).

Disability

Grandparent support of mothers caring for a child with a disability: Impacts for maternal mental health

Crettenden, A. *et al.* (2018), *Research in Developmental Disabilities*. Vol 76, May 2018 Issue

This study aimed to update and extend research into mothers' perceptions of grandparent support with care, and impacts for maternal psychological well-being. Most support was offered by maternal grandmothers who had more contact and closest relationships with mothers. Maternal distress was related to maternal grandmothers' health and relationships with maternal grandfathers. Grandparents are important supports for mothers of children with disabilities: mothers lacking support from their own parents are particularly vulnerable.

Using Discrete-Choice Experiment Methods to Estimate the Value of Informal Care: The Case of Children with Intellectual Disability

Arora, S. *et al.* (2018), *Pharmacoeconomics*.

This research produces a preference-based monetary valuation of informal care provided to children with intellectual disability (ID) that can be directly applied in economic evaluations. This study produces a value of informal care provided to children with ID that can be directly applied in economic evaluations. The study shows that informal care tasks are not valued equally. Caregivers placed the most value on receiving assistance with social support, which may reflect the time spent by caregivers on these tasks.

Mental Health

A bittersweet relationship: What does it mean to be the caregiver of a patient with bipolar disorder?

Vargas-Huicochea, I. *et al.* (2018), *International Journal of Psychiatry*. Vol 64, Issue 3

Aware of the importance of the role played by informal caregivers (especially the family) in the stability and evolution of patients with bipolar disorder, this study seeks to explore the perception that family members responsible for bipolar persons have of themselves as caregivers of these patients. It is necessary to integrate evaluation and attention for patients' caregivers, recognizing them as individuals and elucidating their constructed meanings and the dynamics established in their relationship with patients.

Drug / Alcohol Dependency

Being a Parent to an Adult Child With Drug Problems: Negative Impacts on Life Situation, Health, and Emotions

Richert, T. *et al.* (2018), *Journal of Family Issues*. Vol 39, Issue 8

This study is about the vulnerability of parents to adult children with drug problems. Most parents reported extensive negative consequences on relationships, social life, and mental health due to their children's drug problems. In general, fathers claimed to feel less of a negative impact than mothers. A more severe drug problem and life situation for the child was associated with a greater negative impact for the parents.

Serious Illness / Chronic Condition

Caregiver burden and its related factors in advanced Parkinson's disease: data from the PREDICT study

Tessitore, A. *et al.* (2018), *Journal of Neurology*. Vol 265, Issue 5

The objective of this study was to describe the burden and the related factors of caregivers of advanced Parkinson's disease (APD) patients either treated with continuous dopaminergic delivery systems or standard therapy. Caregiver burden showed a tendency to be lower when patients are treated with LCIG than with CSAI or SOC.

Feasibility, useability and acceptability of technology-based interventions for informal cancer carers: a systematic review

Heynsbergh, N. *et al.* (2018), *BMC Cancer*. Vol 18, Issue 1

The objectives were to assess the feasibility, useability and acceptability of technology-based interventions among carers of people living with cancer. Overall, carers rated the content of the interventions as appropriate and reported improved knowledge and communication. Acceptability was further demonstrated as carers preferred the flexibility available with web-based interventions. Technology-based interventions are suitable for use among carers of people with cancer.

Caring for the Carers

Edwards, L. *et al.* (2018), *A Practical Approach to the Care of Adolescents and Young Adults with Cancer*, Springer International Publishing.

Caring for adolescents and young adults with cancer is a multi-dimensional role shared by many. This book explores the developmental and social tasks faced by the young person, as well as the recognised impact of the diagnosis of cancer on both the young person and their carers in the wider social system. Support for carers, including staff, is important to help carers feel safe and contained, including promotion of self-care to aid understanding and resilience and to minimise stress and burnout.

Palliative Care / Bereavement

“Never at ease” – family carers within integrated palliative care: a multinational, mixed method study

Gülay, A. *et al.* (2018), *BMC Palliative Care*. Vol 17, Issue 1

Investigates burdens and rewards associated with family caregiving and what family carers find helpful in their contact with professionals from integrated palliative care initiatives (IPC-i) and other services. Data suggest that, most IPC-i did not pay enough attention to the needs of family carers, and did not offer proactive care and access to supportive resources to them. We recommend recognizing family carers as part of the 'unit of care' and partner in caregiving, to improve their knowledge about, and access to, the support available.

Family Caregivers' Preparations for Death: A Qualitative Analysis

Breen, L.J. *et al.* (2018), *Journal of Pain and Symptom Management*. Vol 55, Issue 6

This study explored family caregivers' preparations for death. Caregivers described the complexities of trying to prepare while feeling overwhelmed with demands of caregiving throughout an unpredictable illness trajectory. The caregivers in the present study were cognitively prepared, some were behaviorally prepared, but emotional preparedness was challenging. Services should not assume that all family caregivers are well-prepared for the death.

Psychological morbidity in family caregivers of people living with terminal cancer: Prevalence and predictors

Areia, N.P. *et al.* (2018), *Palliative & Supportive Care*.

This study aimed to assess psychological morbidity in family caregivers of persons with terminal cancer in terms of psychological distress, depression, anxiety, somatization, and complicated anticipatory grief, and to determine which factors may influence these responses. Results revealed an alarming prevalence of psychological morbidity in caregivers, making it crucial to move from a patient-centered to family-centered approach to reduce family maladjustment when facing the imminent death of a family member.

Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach

Ewing, G. *et al.* (2018), *Palliative Medicine*. Vol 32, Issue 5

This study aims to explore whether and how family carers are currently supported during patient discharge at end of life; to assess perceived benefits, acceptability and feasibility of using The Carer Support Needs Assessment Tool (CSNAT) Approach in the hospital setting to support carers. The study identifies a novel intervention, which expands the focus of discharge planning to include assessment of carers' support needs at transition, potentially preventing breakdown of care at home and patient readmissions to hospital.

Aged

The third person in the room: The needs of care partners of older people in home care services-A systematic review from a person-centred perspective

Anker-Hansen, C. *et al.*, (2018). *Journal of Clinical Nursing*. Vol 27, Issue 7-8

This study aims to identify and synthesise the needs of care partners of older people living at home with assistance from home care services. The carers in home care services need competence to identify and meet the needs of care partners. The implementation of person-centred values in home care services can contribute to meet the needs of care partners to a greater extent than today. Future research on the needs of care partners of older people with mental health problems needs to be undertaken.

Dementia

Effectiveness of interventions for co-residing family caregivers of people with dementia: Systematic review and meta-analysis

Abrahams, R. *et al.*, (2018). *Australian Occupational Therapy Journal*.

The aim of this study was to evaluate the effectiveness of multicomponent interventions on four outcomes for co-residing family caregivers of people with dementia. Many types of multicomponent interventions appear beneficial on all of the four specified outcomes. The literature presents a trend that multicomponent interventions consisting of a combination of counselling, support groups, education, stress and mood management or telephone support are important strategies within an effective multicomponent intervention.

Caring for Carers of People with Dementia: A Protocol for Harnessing Innovation Through Deploying Leading Edge Technologies to Enable Virtual Support Groups and Services

Parkinson, L. *et al.* (2018). *Studies in Health Technology and Informatics*. Vol 246

The primary objective of this project is to examine the response of isolated rural carers for older people with dementia to a videoconference (VC) based peer support and information program. Will participation in the program improve self-efficacy, quality of life, and mental health? Secondary objectives are to develop a VC based peer support program for isolated rural carers for older people with dementia and to assess the feasibility of VC technology for enhancing social support to family caregivers in their homes.

Assessment of the mental health of carers according to the stage of patients with diagnosis of Alzheimer-type dementia

Yazar, T. *et al.* (2018), *Neurological Sciences*. Vol 39, Issue 5

In this study, the aims were to assess the mental health state of carers for patients with Alzheimer-type dementia (AD) according to stage of disease and to collect data with the aim of determining precautions to reduce the load of the patient and disease on the carer. The data shows that with progressing disease stage, the load on the carer increases and mental health begins to dysfunction.

Effect of multicomponent interventions on competence of family caregivers of people with dementia: A systematic review

Ying, J. *et al.* (2018), *Journal of Clinical Nursing*. Vol27, Issue 9-10

This review aims to summarise and evaluate multicomponent interventions focused on improving the competence of family members of people with dementia (PwD) who undertake caregiving tasks. The current study provides recommendations regarding the formulation and implementation of interventions based on relevant literature. In view of existing research, researchers should conduct an in - depth study in this area and provide evidence - based interventions to support family members caring for PwD.

How best to assess quality of life in informal carers of people with dementia; A systematic review of existing outcome measures

Dow, J. *et al.* (2018), *PLoS One*. Vol 13, Issue 3

This study reviewed suitable instrument(s) for measuring the adverse effects on carers of persons with dementia's (PwD) psychological, physical, and social wellbeing, and quality of life. Ten instruments were reviewed. The Carer well-being and support questionnaire (CWS) was found to be the most appropriate instrument to recommend for the assessment of quality of life in informal carers of people with dementia at present. All instruments included in this review would benefit from more rigorous evaluation.

Moving through predeath grief: Psychological support for family caregivers of people with dementia

Meichsner, F. *et al.* (2018), *Dementia*.

This study described sources of grief carers reported during therapy and investigates how therapists can support them. Results suggest carers experienced loss of companionship with their care recipient and ambiguous loss that resulted in intense grief that was difficult to manage. Therapists responded by supporting carers to acknowledge their losses and identify individual ways to cope with and accept loss and grief.

Understanding and Measuring the Wellbeing of Carers of People With Dementia

Cunningham, N.A. *et al.* (2018), *Gerontologist*.

This study aimed to determine how the wellbeing of carers of people with dementia is understood and measured in contemporary health research. Without clear consensus, health professionals must be careful when using the term "wellbeing". To help inform healthcare policy and practice, we offer a starting point for a richer concept of wellbeing in the context of dementia that is multi-faceted to include positive dimensions of caregiving in addition to recognized aspects of burden.

Recognition & Support of Carers



A transformative approach to systems theory in caregiving research

Cash, B. *et al.* (2017), *Qualitative Social Work*.

This paper illustrates how systems theory can be used in social work research design to understand the systemic issues associated with spousal care in rural Australia. The purpose of this paper is to provide an illustration of a research design that explores the systemic complexity of spousal caregiving. This application of systems theory to research presents an innovative opportunity for social work research to reflect long-established practices of understanding complex phenomenon within its sociocultural context.

Coproduction of a Theory-Based Digital Resource for Unpaid Carers (The Care Companion): Mixed-Methods Study

Dale, J. *et al.* (2018), *JMIR Aging*. Vol 1, Issue 1

This study aimed to coproduce a digital program for carers of older people to promote resilience and coping through effective use of information and other Web-based resources. Four overlapping stages were: understanding the ways in which Web-based interventions may address challenges faced by carers, identifying target behaviors for the intervention, identifying intervention components, and developing the intervention prototype. An engaging, relevant, applicable, and feasible Web-based intervention was produced.

Evaluation for a Caring Society

Visse, M. & Abma, T.A. (2018), *Evaluation and Society*, Information Age Publishing.

This book highlights views on responsive, participatory and democratic approaches to evaluation from an ethos of care. It critically scrutinizes and discusses the invisibility of care in our contemporary Western societies and evaluation practices that aim to measure practices by external standards. Alternatively, the book proposes several foci for evaluators who work from a care perspective or wish to encourage a caring society.

Carer Health & Wellbeing

Assessment of the sense of coherence in the perceived burden and in the adherence to a psycho-educational program for informal caregivers of dependent persons

Turró Garriga, O. *et al.* (2018), *PubMed NCBI*.

This study aimed to determine the impact of the sense of coherence (SOC) on the perceived burden and to determine if these characteristics are associated with adherence to a psycho-educational program for informal caregivers. The sense of coherence and mainly the meaning, is a characteristic to take into account for the adaptation of interventions in caregivers and provide them with greater equity working more on the people who need it the most (lower SOC and greater burden).

Translation, Face and Content Validity of Burden Scale for Family Caregivers

Jamali, A.R. *et al.* (2018), *Middle East Journal of Rehabilitation and Health*. Vol 5, Issue 1

Informal caregivers who give regular care to their relative, needing help for a time, are at risk of many difficulties such as financial dependency, anger, wandering, social problems and communication problems. This study aimed to translate and validate a Persian version of “burden scale for family caregivers-short (BSFC-s)” to measure the burden of informal caregivers. The BSFC-s was translated into Persian and its face as well as content validity were acceptable. Further study is needed to evaluate its reliability and validity.

Social Inclusion, Relationships & Community Participation

The effectiveness of support groups: a literature review

Worrall, H. *et al.* (2018), *Mental Health and Social Inclusion*. Vol 22, issue 2

Support groups are a common feature of the mental health support engaged by carers and consumers. The purpose of this paper is to update and consolidate the knowledge and the evidence for the effectiveness of mental health support groups. The results show that there is a consistent pattern of evidence, which confirms the effectiveness of professionally facilitated, family-led support groups, psychoeducation carers support groups, and professionally facilitated, program-based support groups for people living with mental illness.

Young Carers

Being we and being me: Exploring the needs of Austrian families with caring children

Nagl-Cupal, M. & Hauprich, J. (2018), *Health & Social Care in the Community*. Vol 26, Issue 4

Investigated the needs of young carers' families in terms of managing daily caring demands, and aimed to contribute to the prevention of children and adolescents assuming inappropriate caring roles. Findings revealed that young carers' families need to live in accordance with their inherent family logic, and indicate that formal support for families with young carers should consider the individuality of caring arrangements with respect to holistic and personal needs, and avoid stigmatising families that integrate children into caring.

Study protocol: young carers and young adult carers in Switzerland

Leu, A. *et al.* (2018), *BMC Health Services Research*. Vol 18

This study considered young carers and young adult carers in Switzerland, including the (currently unknown) number of these younger carers, as well as the extent and kind of their caring activities and the outcomes for their health, well-being, psycho-social development, education, transitions to adulthood, future employability and economic participation. The study will collect important data on the awareness, extent, kind and impact of caring amongst children and young people and link these findings with evidence from other countries.

Using Adverse Childhood Experience Scores to Better Understand the Needs of Young Carers

Spratt, T. *et al.* (2018), *The British Journal of Social Work*.

This article reports on research into the experiences of young carers in Barnardo's Young Carers and Action for Children Young Carers projects. The results merit further research involving larger numbers. Implications for practitioners and policy makers include screening for adverse childhood experiences (ACEs) in assessments and development of bespoke services to meet the needs of those with high ACE scores, such as young carers with a parent with a mental illness.

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