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

Estimating service demand for respite care among informal carers of people with psychological disabilities in Australia


This paper estimates demand for respite care among informal, primary carers of people with a psychological disability. One-quarter of these carers reported service demand for respite care, of whom one-third had used respite services in the past three months and four-fifths had an unmet need for any or more respite care. Lack of suitable, available respite care models was a barrier to utilisation. Increased coverage of respite services, more flexible service delivery models matched to carers’ needs and better integration with other support services are indicated.

Parental report of the diagnostic process and outcome: ASD compared with other developmental disabilities


This analysis examined the experiences of parents of children with ASD compared with parents of children with some other developmental disability. Despite substantially earlier parental concerns about their child’s development, the ASD group received their current diagnosis about 7 months later on average, than did children in the group diagnosed with other developmental delay. Parents in the “Current ASD” group were more likely to report that the health professional said nothing was wrong or that the child might “grow out of it,” emphasising a common parental complaint.
Parenting stress and child behaviour problems among parents with intellectual disabilities: The buffering role of resources

This study evaluated resources as moderators of the association between child behaviour problems and parenting stress. Parents experienced more stress with regard to their children than towards their own functioning and situation. Large support networks decreased the association between child behaviour problems and parenting stress. Stress among parents with ID is focused on problems with the child, especially when little social support is available.

Caregivers’ voices: The experiences of caregivers of children who sustained serious accidental and non-accidental head injury in early childhood

This study describes the experiences of carers of children who sustained a serious head injury before the age of 2 years. Findings reveal the broad impact of serious childhood head injury on carers, specifically the distress and burden brought about through lack of information, challenges in accessing support and inconsistent care. Recommendations for developing a quality ‘model of care’ and improving ease of access to supports for caregivers are provided.

Family carers’ experience of the need for admission of their relative with an intellectual disability to an Assessment and Treatment Unit

This study aimed to explore family carers’ experience and their relationships with professionals when an individual with an intellectual disability was admitted to a National Health Service Assessment and Treatment Unit. Findings illustrate how this experience resulted in higher levels of anxiety, stress and uncertainty about the future of their relative and their identity as a carer. Significantly, professionals are identified as having a pivotal role in influencing how carers come to view their sense of self, identity, value and importance.

Mental Health

Quality of life and social isolation among caregivers of adults with schizophrenia: Policy and outcomes

Sixty Australian carers were assessed regarding their quality of life, psychological distress, social isolation and caregiving experience. Carers were ten times more likely to be socially isolated and quality of life was significantly less than matched community samples. Carers still face considerable challenges to their wellbeing as they support people living with mental illness, in spite of progress in the development of policy and services.
Distress in caregivers of a family member with serious mental illness
This study explored distress in caregivers of a family member with serious mental illness (SMI). Caring for a son or daughter or devoting 20 hr a week or less to caregiving was associated with lower distress levels. Higher numbers of difficult behaviours exhibited by the person diagnosed were associated with higher family discord.

An empowerment approach to family caregiver involvement in suicide prevention: Implications for practice
This review outlines the experience of caring for a loved one at suicide risk, including potential barriers to involvement, risk and protective factors, and impact on the caregiver. We propose an existing caregiver empowerment model, Creativity, Optimism, Planning and Expert information (COPE), that can be applied to any existing suicide prevention model to assist families in the treatment of clients who are at risk for suicide.

The perceived stigma of mental health services among rural parents of children with psychosocial concerns
This study examined parents’ perceptions of stigma regarding mental health services for their child. Parents endorsed low levels of stigma around services. Having a younger child and a history of prior services was associated with greater willingness to seek services. Stigma does appear to present as a barrier, but only for some parents. Providing mental health services to young children and their parents in some non-traditional settings may increase access.

Support for and from aging mothers whose adult daughters are seriously mentally ill
This article discusses the ways in which support is exchanged in families coping with serious mental illness. This study focuses on interviews obtained from grandmothers aged 52-90 who are in contact with their daughters who have a mental illness. Grandmothers provided several kinds of support to their mentally ill adult daughters and to their grandchildren, who also supported the grandmother in numerous ways. It is important to assess the existing strengths of the intergenerational family context.
**Chronic Condition**

**Caring for people with severe myalgic encephalomyelitis: An interpretative phenomenological analysis of parents’ experiences**


This study aimed to give voices to those who care for individuals with myalgic encephalomyelitis. Results included themes of identity change, guilt, feeling like outsiders, uncertainty, changing perceptions of time, coping mechanisms, and improvement/symptom management. Findings could inform the development of carer-focused interventions and provide vital information to health professionals about parent–carers’ lived experience.

**Family caregiving for adults with sickle cell disease and extremely high hospital use**


This study investigated coping with chronic illness in the adult patient–caregiver relationship for sickle cell disease. Caregivers attributed disruptions to the disease’s variability, tensions in how much support to give, and adults’ inability to fulfil parental obligations. They expressed fears of patients’ increasing age, declining health, and early death.

**Serious/Terminal Illness**

**Spouse cancer caregivers’ burden and distress at entry to home hospice: The role of relationship quality**


This study focuses on relationship quality in spouse caregivers in cancer home hospice. Relationship quality significantly predicted caregiver burden, which completely mediated the relationship between caregiver relationship quality and distress. Caregivers whose social contexts place them at risk for greater distress may benefit from increased clinical attention or intervention.

**A systematic review and thematic synthesis of quality of life in the informal carers of cancer patients with cachexia**


This paper identifies quality of life issues that are relevant to carers of cancer patients with cachexia. The complexity of caring for a cancer patient with cachexia translates into a range of problems and experiences for informal carers. By addressing the impact of caring for a patient with cancer cachexia on carers, both caregiver and patient quality of life may improve.
Parents of children with cancer: At-risk or resilient?


This study examined adjustment in parents of children with cancer. Rates of current and lifetime post-traumatic stress disorder in parents of children with cancer were low, and did not differ from comparison parents. Psychological growth was higher in parents of children with cancer than in comparison parents regardless of time since diagnosis. Parents of children with cancer demonstrate resilience to this challenge.

Approaches to capturing the financial cost of family care-giving within a palliative care context: A systematic review


A systematic review was undertaken to identify literature relating to the financial costs and impact of family care-giving at the end of life. Calculation of costs was most often based on recall by patients and family caregivers, in some studies combined with objective measures of resource use. While the studies in this review provide useful data on approaches to capturing costs of care-giving, more work is needed to develop methods which accurately and sensitively capture the financial costs of caring at the end of life.

Aged & Dementia

Enhancing caregivers’ understanding of dementia and tailoring activities in frontotemporal dementia: Two case studies


This study describes the Tailored Activities Program (TAP) in two people diagnosed with Frontotemporal Dementia (FTD). TAP is an intervention program that prescribes personalised activities to reduce difficult behaviours of dementia. A 51-year-old woman could consistently engage in more activities post-intervention, with improvements to behaviour, function and caregiver confidence. A 63-year-old man engaged well in the prescribed activities, with reduced carer distress regarding challenging behaviours and improved caregiver vigilance.

Risk of cognitive and functional impairment in spouses of people with dementia: Evidence from the Health and Retirement Study


We examined whether having (i) a spouse with dementia and (ii) a spouse who requires assistance with activities of daily living predicted cognitive and functional impairments. Findings suggest that caregivers, especially men, and low-income individuals who have a spouse with dementia are more vulnerable to adverse cognitive outcomes.
The role of coping strategies in psychological outcomes for frontotemporal dementia caregivers


Caregiving for a person with frontotemporal dementia (FTD) is related to poor caregiver outcomes. Coping strategies adopted by caregivers are known to influence psychological outcomes in other dementia caregiver populations, however, their influence on psychological outcomes in FTD caregivers is poorly understood at present. This study identifies variables amenable to clinical interventions that can improve caregivers’ well-being: specifically, caregiver strain and coping strategies.

Cognitive–behavioral therapy (CBT) versus acceptance and commitment therapy (ACT) for dementia family caregivers with significant depressive symptoms: Results of a randomized clinical trial


The efficacy of acceptance and commitment therapy (ACT) and cognitive–behavioural therapy (CBT) for dementia family caregivers’ was analysed through a randomized controlled trial. Significant changes at post-intervention were found in leisure and dysfunctional thoughts in both ACT and CBT, with changes in experiential avoidance only for ACT. ACT seems to be a viable and effective treatment for dementia caregivers.

Reactions to driving cessation: A qualitative study of people with dementia and their families


This paper explores psychosocial and adjustment issues following driving cessation for people with dementia and their supporters. Carers who were supportive of driving cessation questioned the legality of it. Most participants minimised the impact of their driving cessation on their supporters. Most supporters were negatively affected by the decision. The findings highlight the need for a more comprehensive process for driving cessation in those with dementia, with closer links to regulatory bodies, and increased support for their carers.
Recognition & Support of Carers

Help or hindrance: How are services and systems viewed by informal care networks?


This study aims to understand the perceptions of members of informal care networks of the role taken by health services in the support of dying people at home. The analysis revealed care by individual practitioners was viewed as “above and beyond” expectations. However, the rules and regulations required by many services, and health system at large, were viewed as impediments to appropriate support of those dying at home. More appropriate care of dying people receiving care at home requires formal services to evaluate their attitudes and conduct towards informal networks.

Working with parents to support their disabled children’s social and school inclusion: An exploratory counseling study


This article synthesises the long-lasting counselling process of a family with a child suffering from a chronic illness. Through the presentation of a case study of a couple who faced a critical situation in the life of their child, this article briefly describes the way the family dynamics were readdressed through this intervention counselling model.

Family carers’ experiences of the Admiral Nursing Service: A quantitative analysis of carer feedback


This study assessed the effectiveness of the Admiral Nurses’ approach from the perspective of family carers who had accessed their service. Whilst some aspects of supporting carers performed less well from the carers’ perspective, overall family carers in receipt of Admiral Nursing support perceived their family-centred approach as helpful/effective.

A telehealth behavioral coaching intervention for neurocognitive disorder family carers


This study examined the impact of two telehealth programs for women caring for an older adult with a neurocognitive disorder. Results provide some initial evidence for the efficacy of a telehealth behavioural coaching intervention compared with basic education and telephone support. Dementia carers, including those living in rural areas, can benefit from accessible and empirically supported interventions that can be easily disseminated across distances at modest cost.
Carer Health & Wellbeing

Hope and subjective well-being among parents of children with special needs
This study examined subjective well-being (SWB) in parents who raise children with special needs. Results revealed that a high level of hope, being in a partnered relationship, and perception of the child’s disability as having some positive influence on central aspects of the parents' life, are all significant contributors to raising parental SWB.

Emotional suppression, caregiving burden, mastery, coping strategies and mental health in spousal caregivers
This study explored the effects of personal resources between caregiving burden and depression in spousal caregivers. The study supports the conditional indirect effect in which burden can affect depression by reducing mastery and increasing disengagement coping simultaneously. The study provides also initial support for the moderating effect of emotional suppression, which can increase the deleterious effects of burden on depression.

The impact of care on family and health-related quality of life of parents with chronically ill and disabled children
This study examines how far the burden of care is associated with health-related quality of life (QoL) in parents, across different illnesses and disabilities. A higher burden of care is associated with higher risks for poor health-related QoL. Social impact and financial burden can help to explain these associations. Interventions should focus not only on the affected child but also on the whole family system and its social integration.

Social Inclusion, Relationships & Community Participation

The positioning of family, friends, community, and service providers in support networks for caring at end-of-life: A social network analysis
This study identified the relative positioning of family, friends, community, and service providers in caring networks. The analysis revealed significant increases in the density of the networks over time. The density of relationships with friends was similar to that other family. Community and service providers had significantly lower density. Qualitative analysis revealed that often service providers were not seen as part of the networks. To avoid carer burnout, it is important not to make assumptions about where carers obtain support but work with each carer to mobilise any support that is available.
Leisure time activities and mental health in informal dementia caregivers


This study examines whether perceived change in leisure activities links stress and burden in dementia caregiving to lower mental health. Analyses demonstrated that perceived changes in leisure activities linked caregiving stress and burden to lower mental health, and that membership in groups engaging in affiliation or social activities attenuates negative effects of caregiving. In particular, engaging in social activities and self-help groups buffered the negative impact of caregiving.

In sickness and in health: Couples coping with stroke across the life span


This study reports findings from interviews of couples coping with stroke. Four primary themes were identified: (1) practical and emotional challenges, (2) relationship challenges, (3) unexpected changes to couples’ anticipated life course, and (4) mobilization of emotional and relationship resources after stroke.

The use of information and communication technologies to support working carers of older people – a qualitative secondary analysis


This study describes nursing and support staff’s experiences of using ICT for information, e-learning and support of working carers of older people. The findings suggest the ICTs to be flexible structures that provided nursing staff with a means and method to support working carers of older people. The use of ICTs provides nurses with a means to offer support to working carers of older people and enables carers to be informed, to learn and to share their burdens with others when caring for an older family member.

CALD Carers

Positive aspects of family caregiving for dementia: Differential item functioning by race


Due to increasing interest in the positive experiences associated with family caregiving, potential demographic group differences were examined. Both Hispanics and African Americans experienced more positive aspects than Whites. African Americans reported that caregiving gave them “a more positive attitude toward life” and enabled them to “appreciate life more” than either Whites or Hispanics.
Coping strategies, caregiving burden, and depressive symptoms of Taiwanese mothers of adolescents with autism spectrum disorder


The effects of the caregiving burden and coping strategies on the depressive symptoms of Taiwanese mothers of adolescents with autism spectrum disorder were examined. Findings indicated that greater use of problem-focused rather than emotion-focused coping was generally associated with lower levels of caregiver burden and fewer depressive symptoms. Awareness of the effects of coping strategies on maternal well-being could serve as a valuable guide for practitioners.

Rural Carers

“A lot of things passed me by”: Rural stroke survivors’ and caregivers’ experience of receiving education from health care providers


This study examined rural stroke survivors’ and caregivers’ experiences of receiving education from health care providers with the long-term goal of optimising educational interactions and interventions for an underserved population. Our results suggest the need for improved access to educational providers, proactive identification of informational needs by providers, greater inclusion of caregivers in education, enhanced communication with information provision, and education from multiple providers using multiple delivery methods at multiple time points.