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**

**Rural carers of people with disabilities: Making choices to move or to stay**


Understanding the factors that rural carers weigh up in making the decision to move or stay can inform the successful implementation of the National Disability Insurance Scheme (NDIS) in rural areas. Participants made decisions about whether to stay living in their rural community or to move to a larger centre according to personal factors, social factors, and economic factors. These factors need to be considered in the roll-out of the NDIS to ensure that rural service users enjoy the benefit of a real choice to live in a rural area without reducing their access to support services.

**Caregiver experiences of supporting adults with intellectual disabilities in pain**


Caregivers have an intimate knowledge of the individuals they care for and are therefore an important source of information on pain experiences. There seems an art to detect pain using existing skills and knowledge of the individual's ways of expressing pain. Despite best efforts, recognizing and treating pain was experienced as complex and ambiguous. Some caregivers described a negative emotional impact and dissatisfaction with the management of pain by health care services.
Parents’ perceptions of the severity of their child’s autistic behaviors and differences in parental stress, family functioning, and social support


This study examined parental stress, family functioning, and social supports among parents’ perceptions of the severity of their child’s autistic behaviours. Parents of children with more severe autistic behaviours reported higher levels of parental stress and poorer ratings of their personal functioning in the family than parents of children with less severe autistic behaviours and typically developing children. The groups did not differ on the parents’ report of the functioning of the family unit or on perceived helpfulness of family social support.

Services and supports for young children with Down syndrome: Parent and provider perspectives


As individuals with Down syndrome are living longer and more socially connected lives, early access to supports and services for their parents will ensure an optimal start and improved outcomes. Parents and providers reflected on key early life issues for children with Down syndrome and their families in five areas: prenatal diagnosis; perinatal care; medical and developmental services; care co-ordination and services; and social and community support. Systems of care are not consistently prepared to provide appropriate family-centred services to individuals with Down syndrome and their families.

Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners


Parents of children with intellectual and/or developmental disabilities experience more stress in comparison to parents of normally developing children. Despite this, there is a subset of parents who remain resilient in the face of significant stress in their lives. The authors conducted a systematic review of research article databases and found support for coping style, optimism, and social support as resilience factors for parents of children with intellectual and/or developmental disabilities. Awareness of variables that promote resilience for parents of children with intellectual and/or developmental disabilities is likely to inform clinical practice through offering new avenues for clinical focus in all phases of family-centred care.
Mental Health

‘We didn’t have a clue’: Family caregivers’ experiences of the communication of a diagnosis of schizophrenia


This study examines family caregivers’ experiences of the communication of a schizophrenia diagnosis. Family caregivers described long and difficult pathways to being given a diagnosis, high unmet needs for information, exclusion from the medical care process and problematic interactions with mental health clinicians. Family caregivers are an integral part of the mental health-care system, and they should be included early in discussions of diagnosis and treatment of a person with schizophrenia.

The role of metacognitions in expressed emotion and distress: A study on caregivers of persons with first-episode psychosis


In first-episode psychosis, the family is considered an important part in the recovery process. This is often accompanied by significant distress. However, little is known about the psychological factors involved. Analysis found that emotional over-involvement and metacognitions independently predicted caregiver distress. The current study is a first step towards understanding the role of metacognitions in caregiver distress, thus opening up for the possibility of using interventions from ‘contextual behaviour therapies’.

‘They’re not witches. …’ Young children and their parents’ perceptions and experiences of Child and Adolescent Mental Health Services


Our aim was to share children and their parents' perceptions and experiences of Child and Adolescent Mental Health Services (CAMHS). Three core themes emerged: Fear of the unknown; Therapeutic engagement; and making services acceptable. Children were able to provide potentially useful opinions of CAMHS. In a time of limited resources it is imperative that the voices of children and their parents are acknowledged in order to improve accessibility and experiences within CAMHS.
Chronic Condition

Systematic review and meta-analysis: Parent and family-based interventions for children and adolescents with chronic medical conditions
This study aimed to quantify the effects of parent- and family-based psychological therapies for youth with common chronic medical conditions on parent, family and child outcomes. Parent- and family-based psychological therapies can improve parent outcomes, with problem-solving therapy emerging as particularly promising.

Serious/Terminal Illness

Development and pilot testing of an online intervention to support young couples' coping and adjustment to breast cancer
Couplelinks is an original, professionally facilitated online intervention tailored to the unique challenges facing young women with breast cancer and their male partners. Completers reported satisfaction with the program overall. Reported benefits were: enhanced communication and self-other knowledge; creation of opportunities for meaningful, cancer-related discussion; affirmation of relationship strengths; and a greater sense of closeness between partners. Partners with particularly elevated distress, or with differential levels of motivation, are less likely to finish.

Aged & Dementia

Caregiver burden in mild cognitive impairment
We studied the rates of burden amongst caregivers of participants with mild cognitive impairment (MCI), and aimed to identify factors in both the caregiver and patient that are associated with significant levels of burden. We found that 36% of MCI-caregivers reported clinically significant levels of burden. Participant behavioural problems contribute most to burden, with participant depression and possibly cognition also having a significant association.
Effects of a psychosocial intervention on caregivers of recently placed nursing home residents: A randomized controlled trial


This study tested the efficacy of a psychosocial intervention for informal caregivers whose care recipients resided in a long-term care facility. The intervention was delivered during the 6-month period following baseline assessment. Caregiver depression, anxiety, and burden improved over time. No treatment effects were found for these outcomes. However, complicated grief was significantly lower for caregivers in the treatment condition.

Familial perceptions of the impact of outcome-focused homecare with older people experiencing dementia and living alone


This paper discusses whether the use of outcome-focused homecare improves the subjective well-being of older people with dementia and their familial carers. All carers expressed an improvement in their subjective well-being and that of their older family member, who appeared more settled as a result of this model of care. These finding will help practitioners consider the use of this model of homecare as a potential alternative to residential care.

Recognition & Support of Carers

Do family meetings improve measurable outcomes for patients, carers, or health systems? A systematic review


The aim of this systematic review was to investigate research exploring the impact of inpatient family meetings on patient, carer, or service outcomes. There is some evidence that inpatient family meetings reduce psychological distress of family carers and assist in meeting their information and support needs, and may help to reduce readmission rates and facilitate entry to continuing care programs.

Circle of care: Extending beyond primary caregivers to examine collaborative caretaking in adolescent development


In the contemporary family, parents rarely are the sole caretakers of their children. This study explored the influences of caregiving networks on youth depression. Data revealed participation of multiple caregivers, but ethnic differences existed in network composition. These differences in network composition are discussed within a sociocultural context, considering how positive relationships with specific caregivers may buffer future depression.
Formal and informal support of family caregivers managing medications for patients who receive end-of-life care at home: A cross-sectional survey of caregivers


This study explores factors related to caregivers’ support with managing medications for end-of-life home hospice patients. Our study suggests that high proportions of caregivers may not have support managing medications for patients receiving hospice care at home. Disagreement about treatment with formal/informal support warrants further investigation.

The Caregiver Ombudsman Outreach Program (Co-Op): Lessons learned for engaging students and impacting the community


We discuss a program designed to serve ethnically-diverse caregivers of older adults. Social work and nursing students participated in all aspects of the project, including development, implementation, and evaluation. This level of involvement facilitates a deep understanding of the interconnections among practice, research, policy, and education, and fosters an interest in and commitment to working with older adults and their families.

Delirium and the family caregiver: The need for evidence-based education interventions


We hypothesized that there is a dearth of information on educating the family caregivers of delirious older patients. Few studies consider the impact of delirium on family caregivers and even fewer focus on how to manage delirium in loved ones. With increased risks to older adult patients, high cost of care, and the preventable nature of delirium, family caregiver education may be an important tactic to improve outcomes for both patient and caregiver.

Carer Health & Wellbeing

The effects of caregiver emotional stress on the depressive symptomatology of the care recipient


This study investigated caregiver emotional stress as a chronic life stressor of an elderly care recipient. Overall, results showed that high levels of emotional stress reported by the caregiver were associated with a higher likelihood of the disabled care receiver reporting depressive symptoms. The findings of this investigation point to the importance of studying caregivers and care receivers as dyads as the stress associated with the caregiving role affects each member.
Dental care utilization among caregivers who care for older adults


The goal of this study was to investigate factors associated with dental care utilisation by informal caregivers. Caregivers with health insurance coverage and higher education were more likely to use dental care; those who had lost more teeth and who were spouse caregivers were less likely to do so.

Social Inclusion, Relationships & Community Participation

Profiles of loneliness in the caregiving unit


This study evaluated profiles of loneliness within the caregiving unit, which was composed of an older care recipient with functional impairment, a family member, and a home care worker. The study provides a needed recognition of the potential interdependence among members of the caregiving unit and calls for research and practice that go beyond the individual level. The assessment of loneliness at the caregiving unit can provide valuable information about at-risk units as well as about the potential effectiveness of interventions that target the entire caregiving unit.

Person Centred Approaches/NDIS

Intellectual disability and complex intersections: Marginalisation under the National Disability Insurance Scheme


This paper questions whether the National Disability Insurance Scheme (NDIS), can meet its aims for people with disabilities who also experience complex social disadvantage. The paper undertakes a critical analysis of the proposed eligibility requirements and assesses the risks of marginalisation for people with intellectual disabilities who also experience other complex individual and social disadvantage. The analysis suggests that under the draft rules the onus is on individuals to prove their eligibility for supports funded by the NDIS on a case-by-case basis and, to prove that receiving such support will reduce their future dependence on the system. This raises a number of issues for those whose experience of disability is tied to complex social disadvantage, and raises questions about the NDIS’s ability to meet its aims in relation to rights, choice, and control. The paper demonstrates the ways in which people with disabilities who are already at risk of disengagement from support systems and social exclusion risk further marginalisation in the context of an NDIS, as it currently appears to have little capacity to recognise and respond to their complex need for disability social support.
CALD Carers

Social workers as “cultural brokers” in providing culturally sensitive care to immigrant families raising a child with a physical disability

Although culturally sensitive care is acknowledged as the gold standard in paediatric rehabilitation, very little is known about the social worker’s role in providing culturally sensitive care to immigrant families raising a child with a physical disability. Study findings showed that social workers’ understanding of culturally sensitive care involved being aware of their biases and how their own cultural or professional orientation may influence their interaction with patients. These results also highlighted common challenges that social workers encountered in providing culturally sensitive care.

The effectiveness of a culturally sensitive cognitive behavioral group intervention for Latino Alzheimer’s caregivers

This study tested the effectiveness of a culturally-sensitive, cognitive behavioural (CBT) group intervention in supporting Latino families’ ability to manage symptoms and improve caregiver well-being. CBT participants reported lower neuropsychiatric symptoms in their relative, less caregiver distress about symptoms, a greater sense of self-efficacy, and less depressive symptoms. Our findings offer preliminary evidence that a culturally tailored, CBT group intervention targeted toward neuropsychiatric symptom management has positive psychological benefits for Latino caregivers.

Rural Carers

Building a rural community caregiver network: Student learning in small town America

The Rural Caregiver Network Project is an example of indigenous coalition-building in a region struggling to ensure that older adults can age-in-place. Through this initiative, a range of elder caregiver interventions were mobilised, coordinated, and sustained. The endorsement of participatory research, evaluation, and programming principles enabled social work students to assume major roles in all aspects of the project while remaining grounded in the realities of rural life. Competence in such a generalist gerontological social work practice perspective is critical in small towns and nonmetropolitan communities.
Outcomes of the ON FIRE peer support programme for children and adolescents in families with mental health problems


Children in families with mental health problems may encounter multiple risks to their well-being. This study aimed to evaluate outcomes from a pilot implementation of the ON FIRE peer support programme. The purpose of ON FIRE is to cultivate hope, resilience and well-being in children and adolescents aged 8–17 years living in families affected by sibling or parental mental health problems. At baseline, participants had significantly greater difficulties compared with Australian norms. At 4 months, there were significant differences in children’s hope and in connections outside the family.

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