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

Family involvement in behaviour management following acquired brain injury (ABI) in community settings: A systematic review


Literature review to examine family involvement in the management of behavioural problems following ABI in the community. Studies revealed findings supportive of family involvement in the management of behavioural problems following ABI, especially where interventions consisted of both educational components and individualized behavioural plans. Findings revealed no significant changes in family burden following behavioural interventions.

Does spirituality facilitate adjustment and resilience among individuals and families after SCI?


The purpose was to investigate the role of spirituality in adjustment and resilience after spinal cord injury (SCI) for the individual and their family. Spirituality was positively associated with life satisfaction, quality of life, mental health and resilience. Using meaning-making and hope as coping strategies in the process of adjustment were highlighted. Clinical implications recommended that spirituality and meaning-making be incorporated during rehabilitation.

The lived experience of parents enabling participation of their child with a physical disability at home, at school and in the community


Aims to explore parents’ thoughts, feelings and concerns while reflecting on their actions, challenges and needs in enabling their child’s participation at home, at school and in the community. Parents’ expressed disappointment from being misunderstood, dealing with the complexity of systems, hindrance their children’s participation by the environment, and a lack of leisure activities for their child. Restrictions in the physical and social environments that urge parents to take actions, to experience challenges and think of needs.
Long-term caregiver mental health outcomes following a predominately online intervention for adolescents with complicated mild to severe traumatic brain injury


To examine the efficacy of counselor-assisted problem solving (CAPS) in improving long-term caregiver psychological functioning following traumatic brain injury (TBI) in adolescents. For lower-income caregivers, the CAPS intervention was associated with lower levels of psychological distress. These findings support the utility of Web-based interventions in improving long-term caregiver psychological distress, particularly for lower-income families.

Participation in a social and recreational day programme increases community integration and reduces family burden of persons with acquired brain injury


To describe and evaluate a new day programme for persons living with an acquired brain injury (ABI). Results indicated decreased severity of challenging behaviour and high satisfaction for participants and family members, suggesting that the programme was effective in reducing participants’ social isolation and increasing appropriate interpersonal behaviours. Participation increased community integration and reduced burden on family caregivers. ABI day programmes help fill the void left after other rehabilitation services end.

Mental Health

Adult children of parents with mental illness: Navigating stigma


This study sought adult children’s experiences of childhood parental mental illness. Participants were aware of social stigmas associated with mental illness during childhood, contributing to their fear of disclosure to others, reinforcing the children's own sense of difference. Further work is required to enhance community understanding about the familial journeys of parental mental illness and the impact of negative-natured stigmas.

The journey effect: How travel affects the experiences of mental health in-patient service-users and their families


This paper explored the perspectives of service-users, family members and staff about the impact of travel issues on the lives of mental health in-patients and carers. Travel problems were a significant issue for many service-users and carers, bound-up with mental health issues and the recovery experience. Travel facilitation through the funding of taxis and the provision of guides was appreciated. Service-users and carers valued distancing from previous home environments.
**Chronic Condition**

**A study on the stressors of primary caregivers of children with asthma**


This study aimed to identify sources of caregiver stress. Primary caregivers taking care of children with asthma paid more attention to household cleaning; this was the biggest physiologic stressor. The biggest psychological stressor was coping with the life-threatening nature of asthma attacks, and the biggest intellectual stressor was drug safety.

**Serious/Terminal Illness**

**The role of spirituality in the lives of mothers of breast cancer survivors**


The study explored how mothers of breast cancer survivors managed adversities associated with this disease and illness. Findings indicate that participants relied on their spirituality for the management of stress and hardship related to having a loved one with breast cancer.

**Estimating the cost of caring for people with cancer at the end of life: A modelling study**


In this study, we estimate the direct and indirect costs for lung, breast, colorectal and prostate cancer patients at the end of life in England and Wales. Total estimated costs for treating people with these four cancers at the end of life are £641 million. Much of this cost is borne by informal care givers. The cost to formal care services of replacing this care with paid care giving would be significant and demand for care will increase as the demographic profile of the population ages.

**Aged & Dementia**

**Journeys with people who have dementia: Connecting and finding meaning in the journey**


This article includes a reflective journey with one person who was diagnosed with early onset dementia, then reflects on research with other people who have dementia and where they find meaning in life, through the process of spiritual reminiscence. The article views dementia through a theological lens that sees those who have dementia as people made in God’s image and the implications this has for their lives and their carers’ lives. Meaning was found to be almost synonymous with relationship and connectedness for participants.
Suicidal ideation in family carers of people with dementia

O'Dwyer, S. T., Moyle, W., Zimmer-Gembeck, M., & De Leo, D. (2015). Aging & Mental Health. The objective was to further explore the rate of suicidal ideation in carers and identify psychosocial risk and protective factors. In tests for mediation, satisfaction with social support and dysfunctional coping had indirect effects on suicidal ideation via depression. Family carers of people with dementia have high rates of suicidal ideation, with depression a risk factor and increasing age and reasons for living as protective factors. Depression and reasons for living should be targeted in interventions to reduce suicide risk in dementia carers.

Homicidal ideation in family carers of people with dementia

O'Dwyer, S. T., Moyle, W., Taylor, T., Creese, J., & Zimmer-Gembeck, M. J. (2015). Aging & Mental Health, in press. The aim of this study was to explore thoughts of homicide in family carers of people with dementia. Seven themes were identified in the data - active thoughts of homicide; understanding homicidal thoughts in others; passive thoughts of death; euthanasia; homicidal thoughts in other caregiving situations; abuse; and disclosing thoughts of harm. Service providers and health professionals are encouraged to identify and support carers contemplating homicide, in a way that recognises the broader social context of carer burden.

Positive aspects of family caregiving of dependent elderly

Sánchez-Izquierdo, M., Prieto-Ursúa, M., & Caperos, J. M. (2015). Educational Gerontology, in press. The study aimed to identify positive aspects of family caregiving and to analyse the relationship between these caregiving rewards and different variables. We confirm the relevance of the caregiver-elder relationship, which can be improved and modified through specific preventive interventions. Our findings indicate that interventions for caregivers of people with dementia should explore ways to find meaning in caregiving.

Theorizing how art gallery interventions impact people with dementia and their caregivers

Camic, P. M., Baker, E. L., & Tischler, V. (2015). The Gerontologist, in press. This study sought to better understand how programs at contemporary and traditional art galleries might play a role in the lives of people with dementia. The emerging theory suggests the art gallery is seen as being a physically valued place that provides intellectual stimulation and offers opportunities for social inclusion that can change how dementia is perceived. The results have potential implications for the use of gallery-based programs in dementia care within public health, healthcare, and museum/art gallery policy and practice.
Recognition & Support of Carers

Translating training in the NYU Caregiver Intervention in Australia: Maintaining fidelity and meeting graduate standards in an online continuing professional education setting


The aim of this study was to develop an Internet-based self-directed training program for Australian healthcare workers to facilitate learning and competence in delivery of a proven intervention for caregivers of people with dementia (the NYUCI). It is aimed at maintaining well-being by increasing social support and decreasing family discord, thereby delaying or avoiding nursing home placement of the person with dementia. This study aimed to transfer knowledge of training in, and delivery of, the NYUCI for an Australian context and consumers.

Informal caregivers’ use of the Internet for caregiving information


This study describes caregivers' use of the Internet for caregiving information. More than half of caregivers searched online caregiving information. Caregivers' use of the Internet was significantly related to age, education, income, primary caregiver status, caregiving strain, self-reported health, and information/service needs.

Behavioral and educational interventions to support family caregivers in end-of-life care: A systematic review


This article synthesizes interventions that support family caregivers in end-of-life care. All interventions improved family caregivers’ outcomes. The cognitive behavioural therapy resulted in positive outcomes. Future studies need to develop tools for assessing family caregivers’ needs, to effectively measure family caregivers’ outcomes, incorporate a cost-effectiveness analysis and find efficient intervention formats and methods.

Towards expanding the acute care team: Learning how to involve families in care processes


This study assesses family and provider openness to expanding the care team to include family participation and introduce the Family Involvement Menu to facilitate family engagement. The study identified patient care activities as promising opportunities for family engagement, as well as barriers to engagement. This strategy has the potential to increase nursing availability for other tasks, enhance relationship building, and is an opportunity to introduce education for family, preparing them for transition of care and discharge.
The role of the Carer Support Needs Assessment Tool in palliative home care: A qualitative study of practitioners’ perspectives of its impact and mechanisms of action

The study aimed to examine practitioner perspectives of the role of the Carer Support Needs Assessment Tool intervention in palliative home care to identify its impact and mechanisms of action. It indicated the Tool made support needs visible, legitimised support for carers and opened up different conversations with carers. Used routinely with all carers, the Carer Support Needs Assessment Tool has the potential to normalise carer assessment and support, facilitate delivery of carer-identified support and enable effective targeting of resources.

Carer Health & Wellbeing

Factors associated with depression in older carers
With the increasing ageing population and reliance on informal carers, this study identifies factors associated with depression in carers in the older age group. Increased hours spent caring and higher levels of neuroticism were all factors associated with depression. The care-recipient diagnosis, other personality traits, attitudes to ageing, leisure-physical activity and domestic-physical activity were not significantly associated with depression. Implications for interventions to target at-risk carers.

The effect of transitions in caregiving status and intensity on perceived stress among 992 female caregivers and noncaregivers
The study evaluated the simultaneous impact of changes in caregiving status and intensity on perceived stress. Transitions in caregiving status and intensity affect caregiver perceived stress. Continuing high-intensity caregivers and those who transition from low- to high-intensity caregiving report the highest stress of all transition groups, suggesting that stress-reduction interventions should target high-intensity caregivers.

A comparative study of caregiver burden in late-onset depression and Alzheimer's disease
The objectives were to compare the caregiver burden in LOD and AD and to identify factors associated with caregiver burden in LOD. This study highlights the finding that caregiver burden in LOD is comparable to that in AD and requires interventions to reduce the caregiver strain.
Social Inclusion, Relationships & Community Participation

Care roles and employment decision-making: The effect of economic circumstance

This article examines the effects of care roles on workers’ intentions to leave their jobs. We find that caring for an ill, frail or disabled family member has significantly lower effects on the turnover intentions of mature-age women with ‘poor’ economic circumstances. We interpret this pattern as reflecting the financial costs associated with the provisioning of these types of family care needs.

Parent–adolescent relationship in youths with a chronic condition

This study assessed how living with a CDD during adolescence, the quality of parent–adolescent relationship and the adolescent’s psychosocial development interact with each other. Adolescents with a CDD had a poorer psychosocial health and a more difficult relationship with their parents. It is essential for health professionals to distinguish between issues in relation with the CDD from other psychosocial difficulties.

Couple relationships among parents of children and adolescents with Autism Spectrum Disorder: Findings from a scoping review of the literature

Aims to explore commonly-held assumptions regarding the risk of couple breakdown in families of children with Autism Spectrum Disorder. Findings include themes related to marriage and divorce rates, relationship satisfaction and conflict, and other significant variables. Strategies such as developing common goals, increasing partner respect, securing social support, reducing stress, and instilling hope are factors which support the development and maintenance of positive couple and co-parenting relationships.

Factors influencing the person–carer relationship in people with anxiety and dementia

The aim of this study was to determine which factors are associated with the quality of the patient-carer relationship and whether these differ between the two perspectives. People with dementia generally rated the quality of relationship higher. This study provides a valuable insight into the impact of mental health on relationship quality for both members of the dyad. The findings emphasise the importance of providing interventions which target mood for both parties, and behavioural problems for people with dementia.
CALD Carers

Self-esteem, social support, and life satisfaction in Chinese parents of children with autism spectrum disorder


The study examined self-esteem, social support, and life satisfaction in Chinese parents of children with autism spectrum disorder, and observed the mediation effects of social support on the relationship between self-esteem and life satisfaction. Social support and self-esteem play a more important role in life satisfaction for parents of children with ASD than those of typically developing children. Life satisfaction is positively related to higher household income, higher self-esteem, and stronger social support for parents.

Male Carers

Dads care too! Participation in paid employment and experiences of workplace flexibility for Australian fathers caring for children and young adults with disabilities


This study explores whether caring for children and young people with disabilities affects paid employment participation of fathers who identify as the secondary caregiver. Over one third of fathers reported that caring had impacted on their job opportunities or career progression. The financial costs of their caring obligations informed many of the decisions fathers made in relation to employment. Implications for paternal well-being, lifelong implications of caring on employment and financial security for families in the Australian context are discussed.

Support needs of fathers of children with ASD: Individual, family, community and ideological influences


Examine how fathers’ needs are influenced by contexts ranging from the immediacy of their child's behaviour to overarching expectations for good fathering. Fathers are responsive and reflective in their parenting and value recreationally based support activities that include their children. Fathers endorse father-to-father support and are interested in mentoring fathers newer to the experience of having a child with ASD. Critical re-examination towards advances in father-friendly practices suggested.
Young Carers

Growing up with an ill parent: An examination of family characteristics and parental illness features
The purpose of the study is to investigate the impact of family characteristics (parental involvement, familial support, stress experienced as a result of parental illness) and parental illness features (severity, duration, recovery status, frequency of symptoms, course) on the psychosocial functioning (depression, anxiety, life satisfaction) of late adolescents who have grown up with an ill parent but no longer live with their parents. Results could have clinical applications for psychosocial interventions in children and families coping with chronic illness.

Young adults’ provision of support to middle-aged parents
This study examined support that young adults provide parents and explanations for that support from both offspring’s and parents’ perspectives. Findings are consistent with solidarity theory, which suggests that high-quality relationships may explain support. The concept of self-enhancement and generativity in middle-aged parents may explain the intergenerational differences in the association between parental disability and support.

Supporting young carers: A qualitative review of young carer services in Canada
This article provides the first known qualitative review of existing young carer programmes in Canada, using interview data with staff at each operational site to review the range of services offered to young carers and document barriers to improving their scope and reach. Findings show that available support services are in a preliminary assistance-mitigation phase, with various constraints related to funding and reach that impede their movement to a model of prevention.

Impact of parental acquired brain injury on children: Review of the literature and conceptual model
The review aims to clarify issues in relation to children’s adjustment following parental acquired brain injury, risk of these children’s well-being and organize the available evidence. In brief, the impact of parental ABI on children reflects the extent of the challenges children face and their preponderant ways of coping with them. Evidence shows that children deal with some common socioaffective as well as achievement challenges. Children’s outcomes appear variable, but clearly at risk and in need of special attention.
Parentification, stress, and problem behavior of adolescents who have a parent with mental health problems


This survey examined the effect and consequences of ‘parentification’ in adolescents who live with a parent with mental illness, and also a possible indirect effect via perceived stress. Results showed that parentification was associated with both internalizing and externalizing problems cross-sectionally, but it predicted only internalizing problems 1 year later. Findings imply that parentification can be stressful for adolescents who live with a parent with mental health problems, and that a greater awareness of parentification is needed to prevent adolescents from developing internalizing problems.

Former Carers

Disorder and disconnection: Parent experiences of liminality when caring for their dying child


This study focuses on parents caring for a child with a life threatening or life limiting illness, conducting interviews with parents of children who had died. Findings reveal parents’ experiences to be characterised by personal disorder and transformation as well as social marginalisation and disconnection. An underlying tension between how transition is subjectively experienced and how it is socially regulated is exposed. A structural failure to recognise the chronic nature of felt liminality can impede parents’ effective transition.

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