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

 Mothers caring for children and young people with developmental disabilities: Intent to work, patterns of participation in paid employment and the experience of workplace flexibility


This study shows that mothers who were in a couple relationship and primary caregivers for their child were less likely to be in paid employment and worked fewer hours than mothers in the general population. Work participation was shown to be strongly related to the severity of child disability. 9 out of 10 mothers were unaware of their right to request a change in working arrangements to assist them to care. Changes in workplace support for carers could improve the financial and social circumstances of families and result in significant benefits to Australia's economy.

Grandmothers raising grandchildren with disabilities: Sources of support and family quality of life


Sources of support and quality of life of grandmother-headed families raising grandchildren with and without disabilities were examined. Informal support was significantly higher for grandmothers raising grandchildren without disabilities. In addition, grandmothers raising grandchildren without disabilities rated satisfaction with all aspects of family quality of life except parenting as significantly higher than grandmothers raising grandchildren with disabilities. Analyses revealed a significant relationship between presence of child disability and satisfaction ratings of family quality of life.
Parent–caregiver experiences with the autism spectrum disorder service delivery system
In this study, caregivers of children with autism spectrum disorder (ASD) were interviewed regarding their experiences with the ASD service delivery system. Emergent themes point to the importance of individual coping strategies. Findings can inform the design of future programs, services, and policies to support caregiver coping and improved service delivery.

Riding the Rapids: Living with autism or disability - An evaluation of a parenting support intervention for parents of disabled children
The aim of this study was to evaluate a group-delivered intervention (Riding the Rapids) which was specifically developed for parents of a child with a disability or autistic spectrum condition. Receipt of the intervention was associated with significant reductions in parent-reported behaviour problems and significant improvements in parenting efficacy and satisfaction. Findings suggest this is a promising intervention for parents of a child with a disability that is likely to be less resource intensive to service providers than individually delivered interventions. Limitations and implications for future research are discussed.

Maternal well-being and child behavior in families with fragile X syndrome
The purpose of this study was to examine the relationships between maternal mental health status, maternal stress, family environment and behavioural functioning of children with fragile X syndrome (FXS). Findings indicated that maternal mental health status was not significantly related to changes in levels of child challenging behaviour, heightened child challenging behaviour was related to improvements in maternal depression over time, and heightened levels of child challenging behaviour was related to increased feelings of maternal closeness toward the child over time. The unexpected nature of the results regarding maternal depression and closeness provides new and more complex hypotheses about how mothers of special needs children demonstrate adaptation and resilience.
Mental Health

The lived experience of involuntary community treatment: A qualitative study of mental health consumers and carers
This paper describes the lived experiences of people subject to community treatment orders (CTOs) and their carers. The lived experience of CTOs is complex: it is one of distress and profound ambivalence. The distress is an intrinsic aspect of the experience of severe mental illness. The ambivalence arises from an acknowledgement that while CTOs are coercive and constrain autonomy, they may also be beneficial. These findings can inform improvements to the implementation of CTOs and the consequent experiences.

Identifying the socio-demographic and clinical determinants of family functioning in Greek patients with psychosis
The aim of this study was to describe the characteristics associated with family functioning in patients with schizophrenia and bipolar disorder. The results of this study suggest that a number of social and clinical factors contributed to the family environment of patients with psychosis. Identifying the determinants of family functioning in psychosis is instrumental in developing understandings regarding the factors which may contribute to the rehabilitation or relapse of the patient and the support required to strengthen positive family interactions.

Chronic Condition

The co-construction of couples’ roles in parenting children with a chronic health condition
This study explored the ways that parents of children who have a chronic health condition co-constructed their parenting roles. A key finding is the diversity of ways in which couples adapted to the parenting challenges they faced. Implications in conceptual, clinical, and research areas are presented.
The impact of chronic pain: The perspective of patients, relatives, and caregivers


This study assessed the impact of chronic pain on the family environment. Chronic pain has a very strong impact on the family, although this is perceived distinctly by patients, relatives, and caregivers. Recognising that factors related to pain affect the family’s well-being, and adopting a global approach to pain that takes into consideration the family’s experiences, should improve therapeutic response, and enhance the patient’s and relative’s quality of life.

Serious/Terminal Illness

A strengths perspective on caregiving at the end-of-life


This paper reports evidence from a subset of data analysed for an Australian study, illuminating a range of strengths frequently obscured beneath the emotional-labour work of caregiving and further sequestered by the chaos of grief. A strengths perspective on caregiving at end-of-life is important because it helps to inform a reconstruction of caring and dying to include dimensions that relate to the growth of human potential and capacity, as well as enabling collaborative partnerships between workers and informal carers.

Talking about sex with health professionals: the experience of people with cancer and their partners


This study examines the experience of discussing sexuality post cancer with health care professionals (HCPs), from the perspective of women and men with cancer (PWC), and their partners (PPWC). Responses revealed dissatisfaction with the unwillingness of HCPs to discuss sexuality, unhappiness with the nature of such discussion, and positive accounts of discussions about sexuality with HCPs. These findings lend support to the notion that people with cancer and their partners may have unmet sexual information and support needs.

Depressive rumination and cognitive processes associated with depression in breast cancer patients and their spouses


The present research is an exploration of the role of depressive rumination in the relationships of intrusive thoughts and appraisal of harm/loss with depression. Findings show that the perseverative practice of dwelling on negative thoughts of loss and harm relates to depressive symptoms. Rumination may be a possible mechanism by which intrusive thoughts and harm/loss appraisals lead to depressive symptoms.
Is sense of coherence helpful in coping with caregiver burden for dementia?


In this study, we examined the association between caregiver burden and sense of coherence (SOC) among caregivers to persons with dementia. SOC was closely associated with personal strain. These results suggest that reinforcement of SOC would contribute to reducing the personal strain.

Self-efficacy and health-related quality of life in family carers of people with dementia: A systematic review


This review explores the role of self-efficacy (SE) in the health-related quality of life (QoL) of carers of people with dementia. A model describing the role of SE beliefs in carer health-related QoL was informed by review findings and discussed in the context of existing conceptual models of carer adaptation. The model might have theoretical implications in guiding future research and advancing theoretical models of caring. It might also have clinical implications in facilitating the development of carer support services aimed at improving SE.

‘The living death of Alzheimer's’ versus ‘Take a walk to keep dementia at bay’: Representations of dementia in print media and carer discourse


This article aims to understand how talk about, and to people living with dementia is constructed. I argue that the presence of individualistic dementia ‘preventative’ behaviour in media discourse is problematic, especially in comparison to other more ‘controllable’ and treatable chronic conditions.

Minimizing confusion and disorientation: Cognitive support work in informal dementia caregiving


This paper explains how informal dementia caregivers attempt to reduce the affected individual's moments of confusion and disorientation through cognitive support work. I identify the motivations driving cognitive support work and discuss the role of lay health knowledge in dementia caregiving. I conclude by considering the utility of cognitive support work as a concept within dementia caregiving.
Deciding to institutionalize: Caregiving crisis, intergenerational communication, and uncertainty management for elders and their children in Shanghai


This study conceptualised the decision-making process around institutionalisation among nursing home residents and their children. Findings suggest that caregiving crises triggered intergenerational communication about caregiving arrangements. This study sheds light on caregiving decision-making dynamics for the increasing aging population across cultures.

Bargaining power, parental caregiving, and intergenerational co-residence


This study examines the effect of changes in parent–child co-residence on caregiving decisions of non-resident siblings. Meeting the needs of the growing elderly population while maintaining them in the community is a particular focus of long-term care policy. To the extent that shared living is an important component of such care, the observed sensitivity of non-resident children's caregiving efforts has implications for the well-being of both disabled parents and their co-residing adult children.

Together but apart: Caring for a spouse with dementia resident in a care facility


This study was designed to better understand the lived experience of spousal caregivers providing care to partners with Alzheimer’s disease in a care facility. Thematic analysis revealed a central, unifying theme ‘together but apart’. The results identify key targets for policy makers and service providers to support positive health and well-being outcomes for spousal caregivers providing care to their partners diagnosed with Alzheimer’s disease and related dementia and living in care facilities.

Recognition & Support of Carers

Virtually supportive: A feasibility pilot study of an online support group for dementia caregivers in a 3D virtual environment


This study investigated a virtual online caregiver support group to bring the support group into the home. Data indicated lower levels of perceived stress, depression and loneliness across participants. Importantly, satisfaction reports also indicate that caregivers overcame the barriers to participation, and had a strong sense of the group's presence. This study provides the framework for an accessible and low cost online support group for a dementia caregiver.
Observing women caregivers’ everyday experiences: New ways of understanding and intervening

This article discusses the practice implications of videographic research examining the everyday lived experiences of caregivers of older adults with chronic illness. Findings suggest that observing women caregivers’ everyday experiences can open new avenues for holistic intervention. Observing nonverbal cues can offer a way for practitioners to better understand caregivers’ realities and to adapt interventions accordingly.

Use of a multiparty web based videoconference support group for family caregivers

This article describes a pilot of a web based videoconference support group for caregivers of persons with dementia. All participants reported positive views of the group and videoconference medium. We concluded that web based support was a positive experience for caregivers, providing them with an acceptable technological alternative to in person support that reduced barriers to attendance by being available in homes.

Carer Health & Wellbeing

Predictors of psychological distress in caregivers of older persons with wet age-related macular degeneration

We aimed to determine the predictors of subjective caregiver distress associated with caring for someone with advanced age-related macular degeneration (AMD). A high prevalence of caregiver distress related to caring for persons with advanced AMD was observed. Level of dependence on the caregiver and presence of comorbid chronic illnesses were independent predictors of the caregiver experiencing psychological distress.

The stress of sadness: The most stressful symptoms for hospice family caregivers

This study investigated the most stressful patient symptoms as reported by hospice family caregivers of cancer and cardiopulmonary patients. The symptoms perceived as most stressful for caregivers were psychological in nature. Study findings suggest that members of the hospice interdisciplinary team should connect patients and their caregivers to various types of support to address psychological symptoms, benefitting patients and caregivers alike.
Positive affect is associated with fewer sleep problems in older caregivers but not non-caregivers
This study examined whether the associations of positive affect (PA) and depressive symptoms with sleep problems differed between caregivers and non-caregivers. Low PA and depressive symptoms were associated with more sleep problems among caregivers. PA and depressive symptoms were not associated with sleep problems among non-caregivers. Interventions to increase PA may reduce sleep problems among older caregivers.

Resilience in families caring for a family member diagnosed with dementia
The aim of this study was to explore factors associated with family resilience in families caring for a family member with dementia. Social support, positive communication patterns, acceptance, optimism, family hardiness, family connectedness, and the effective management of symptoms facilitated the resilience process in these families. Findings of this study could be used to develop interventions tailored to the needs of these families caring for dementia patients to create a family environment that enhances adjustment and adaptation.

Social Inclusion, Relationships & Community Participation
Social support and mastery influence the association between stress and poor physical health in parents caring for children with developmental disabilities
This study sought to explore the psychosocial predictors of poor physical health in parents of children with developmental disabilities. Stress and mastery, but not social support and problem behaviours, were significant predictors of poor physical health. However, those parents who were higher on mastery reported less stress and better physical health; furthermore, those parents high on social support and low in stress had better physical health. These results indicate that the paths between psychosocial factors and poor physical health in the caring parents are working synergistically rather than in isolation. They also underscore the importance of providing multi-component interventions that offer a variety of psychosocial resources to meet the precise needs of the parents.
Mothers’ narratives about having a child with cancer: A view through the attachment lens

Bishop, S., Stedmon, J., & Dallos, R. (2014). Clinical Child Psychology and Psychiatry, in press. This study explored mothers’ narratives about having a child with cancer through an attachment lens. The results showed marked differences between the narratives of mothers classified as Type B pattern of attachment (balanced integration of affect and cognition) and those classified as Type A (focus on cognition and dismissal of affect).

A challenging fit: Employment, childcare, and therapeutic support in families of children with autism spectrum disorders

Houser, L., McCarthy, M., Lawer, L., & Mandell, D. (2014). Journal of Social Service Research, in press. This study explores families’ experiences prior to, during, and soon after their child’s ASD diagnosis. The authors identify obstacles to a sustainable degree of work-family life fit: performance pressures, demands of care coordination, and concerns about caregiver quality and accessibility. Recommendations derived from parent-reported strategies for addressing these obstacles include: improving the quality of and access to care management, developing and making accessible a variety of options for combining therapy and care, and expanding awareness of and access to family leave policies and other work flexibility options.

Person Centred Approaches / NDIS

Will the National Disability Insurance Scheme improve the lives of those most in need? Effective service delivery for people with acquired brain injury and other disabilities in remote Aboriginal and Torres Strait Islander communities

The aims of National Disability Insurance Scheme (NDIS) are to provide person-centred care to all Australians with a significant and ongoing disability. Historically, however, service provision in regional areas of Australia lags behind more densely populated centres. Aboriginal and Torres Strait Islanders living with disability are already significantly marginalised. Further to this, people with an acquired brain injury (ABI) are very often misunderstood and overlooked. Equitable benefit can only be achieved if specialised measures are implemented to appropriately screen for incidence of ABI; disability services are resourced to overcome pre-existing disadvantage, and education, training and recruitment of Aboriginal and Torres Strait Islanders with the NDIS is undertaken to lead attitudinal changes in community to disability and health services. This paper concludes with recommendations for the NDIS to meet its laudable objectives.
CALD Carers

Brothers’ experiences caring for a sibling with Down syndrome
This study examined the caregiving experiences of Taiwanese men with their siblings with Down syndrome (DS). The results of the study show that the Taiwanese brother caregivers were raised according to the cultural norm, because of which they accepted the caregiving responsibility, even though they had rarely been included in the early life of their sibling with DS. Greater attention must be paid to the promotion of earlier involvement of brothers in the life of their sibling with DS, and the special challenges surrounding a brother giving care to a sister with DS.

Rural Carers

Coping with cognitive impairment and dementia: Rural caregivers’ perspectives
This paper describes how rural caregivers cope with caring for a loved one diagnosed with mild cognitive impairment or dementia. Analyses of coping revealed use of social support, engaging in relaxing and physical activity, and cognitive reframing. In addition, caregivers reported strong faith and religiosity, and to a lesser frequency behavioural changes, checking in with the person with dementia via telephone, and joint activity. The current data suggest that these caregivers manage well and adopt adaptive coping strategies to meet the demands of the caregiving role.

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