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-centred music therapy to promote social engagement in young children with severe autism spectrum disorder: A randomized controlled study


This study investigated the impacts of family-centred music therapy (FCMT) on social engagement abilities. Analysis of parent interviews showed that the parent–child relationship grew stronger. FCMT improves social interactions in the home and community and the parent–child relationship, but not language skills or general social responsiveness.

Parental perceptions of information needs and service provision for children with developmental disabilities in rural Australia


There is very limited research that gives voice to parents regarding challenges faced by them due to their location in rural regions. Within the constraints of limited rural service provision, there are still opportunities for considerable improvements, through focussed in-service training to narrow the information gap, improve provider-client interaction around attitudinal issues and uptake of tele-health to minimise the long waiting times and the need to regularly travel long distances to access services and setting up online support groups.
Parental and practitioner perspectives on raising an adolescent with a disability: A focus group study


This study examined the challenges faced by parents of teenagers with a disability to determine the need for a tailored parenting program for this population. The results indicated that parents have difficulty planning and facilitating transitions for their adolescent children, managing behavioural problems due to these problems being unique to this developmental period and because some of the parenting strategies that were useful when their children were younger were no longer applicable. These results suggest that parents of adolescents with a developmental disability could benefit from a parenting program and that an existing evidence-based parenting program should be modified.

‘I never thought I would have to do this’: Narrative study with siblings-in-law who live together with a family member with a disability


This study aims to gain an insight into the perspectives of siblings-in-law about the decision to live together with a family member who has a learning disability. The decision to live together usually begins with a crisis. However, the decision process is a complex mechanism; it involves dynamics and events within a family (between family members both with and without blood relationships) and is intensified by experiences within a society that holds different views about families and disability.

Mental Health

Factors affecting disruption in families of adults with mental illness


This study examined relationships between vulnerability/risk and protective factors, and family functioning in women family members of adults with serious mental illness. Family disruption was greatest in women who provided direct care and whose family member had major depression, followed by bipolar disorder, schizophrenia, and panic disorder. Sense of coherence and resourcefulness were associated with lower family disruption, but did not mediate the effects of caregiver strain. Interventions restricted to one family member may be insufficient for improving the family functioning.
Predictors of depression among caregivers of older adults with severe mental illness

This study explored factors influencing negative psychological outcomes experienced by caregivers of older adults with severe mental illness. Low income, care recipient gender, poor health, problems dealing with care recipient's symptoms and the interaction of health and problems dealing with symptoms were associated with higher rates of depression.

Building collaboration in caring for people with schizophrenia

The purpose of the present study was to explore the relationship between community psychiatric nurses and primary caregivers of people with schizophrenia. Nurses and primary caregivers used strategies to establish trust in each other before engaging their concerns and needs. Later, mutual preparation for caregiving, cooperating on patient care and monitoring outcomes were jointly employed in order to promote a healthy family life for patients.

Families parenting adolescents with substance abuse - Recovering the mother’s voice: A narrative literature review

In this literature review, we review published research to capture a historical perspective of addiction and family. We analyse the experiences of parents with alcohol- and drug-dependent children, to emphasize the need for a more in-depth exploration of mothers’ experiences. Such exploration may advance nurses’ understandings of individual, familial, and social complexities of parenting an addicted child.

Drug/Alcohol Dependency

Evaluation of a self-help group for parents of substance addicted offspring: A mixed methods approach

The effectiveness of the self-help method for parents of substance addicted offspring was assessed in parents attending self-help groups. Results indicate that the self-help method contributes to the decrease of anxiety, the adoption of effective coping strategies, and the improvement of family dynamics.


**Chronic Condition**

Moderators of the efficacy of a psychosocial group intervention for children with chronic illness and their parents: What works for whom?


This study investigated psychosocial characteristics of children and parents as predictors of the effect of a group intervention for children with chronic illness and their parents. Children who are more “at risk” appear to gain more from participating in an intervention, especially if their parents are involved as well. However, the benefit of parents’ involvement may depend on the quality of the parent–child relationship.

**Serious/Terminal Illness**

Experiences of cancer caregiving in socioeconomically deprived areas of Attica, Greece


The shift of the majority of cancer care from inpatient to outpatient settings has given rise to a number of issues that have not yet been adequately addressed. We conducted in-depth interviews with family cancer caregivers residing in socioeconomically deprived areas. We identified three major themes: (a) the truth within boundaries, focusing on the flow of information in the triad doctor–caregiver–patient; (b) the evil called “cancer,” reflecting caregivers’ perceptions of the illness; and (c) being left “high and dry,” reflecting participant experiences of home-based care. This study underlines the need for safeguarding the rights of chronically ill patients and ensuring that informal cancer care, apart from a cost-effective solution, will also be an efficient one.

**Aged & Dementia**

Carers: The navigators of the maze of care for people with dementia - A qualitative study


This research sought to investigate the experiences of people with dementia and their carers when transitioning home from hospital. The paradox of the care experience in the acute setting, whereby the carer was invited to deliver care, yet was excluded in staff decisions about that care, challenges the current communication and coordination of care. This study highlights the need to acknowledge the expertise of the carer, and their need for support.
Transitioning from caregiver to visitor in a long-term care facility: The experience of caregivers of people with dementia


The aim of this study was to explore the experiences of caregivers during their transition from day-to-day caregiver of a person with dementia to a visitor in a long-term care facility. Findings revealed that it was difficult for the caregiver to transition to their new role of visitor; negative reactions of grief and loneliness were coupled with positive feelings of relief and reassurance that their relative would be well cared for and safe in the long-term care facility.

Ageing siblings: Supporting new care partnerships


The purpose of the article is to highlight the needs of sibling care partnerships and discuss how the support group model can address some of the challenges faced by this population. Ultimately, the article argues for the development of services geared specifically for older adult siblings caring for each other for the first time in later life.

Intentions of college students to serve as informal caregivers for their older relatives: Theory of planned behavior approach


A need exists to examine the intentions of college students to assume the role of informal caregivers. Students’ quality of interaction with older relatives correlated with intentions to serve as informal caregivers. Implications of the study suggest health care providers, geriatricians, health educators, and patient educators should become involved in the education necessary to assist this young group of informal caregivers.

Recognition & Support of Carers

The space of family care-giving in Australian aged care facilities: Implications for social work


This paper examines the role of family carers in residential care facilities. The findings provide important guidelines for social work in this setting, including the acknowledgement of families in care-giving, genuine partnerships between staff and families, and family-inclusive policies within facilities. In addition, this paper highlights how the social work profession and the residential care sector more generally can strengthen their person-centred focus, engage with families and lessen the marginalisation of families in care-giving.
Reaching out or missing out: Approaches to outreach with family carers in social care organisations


This study aimed to describe different ways of working with family carers in adult social care departments and to collect the views of a range of stakeholders about the advantages and disadvantages of the approaches that were identified. The article highlights important differences between outreach and the provision of information. It concludes that organisations providing support for carers need to consider the advantages and disadvantages of different models of outreach as they develop carers' support and the extent to which different models might be more effective than others in reaching particular types of carer.

Supportive practice with carers of people with substance misuse problems


This article draws on a study of carers' workers (professionals whose role entailed a specific remit to work with carers) and family carers. Key themes were those of insecure funding of voluntary sector carer services; balancing generic support for family carers and specific support for certain groups of carers; and feelings among carers that the drug-and-alcohol problems experienced by the person they were supporting contributed to them feeling excluded from general carers' support.

Carer Health & Wellbeing

The physical functioning and mental health of informal carers: Evidence of care-giving impacts from an Australian population-based cohort


This study investigated the impact of care-giving on the mental and physical health of informal carers, taking account of contextual factors, including family and work. The study found that not all carers suffer adverse health impacts; however, the combination of high levels of care-giving with workforce participation can increase the risk of negative physical and mental health effects (particularly in female carers). Working carers providing high levels of care represent a vulnerable subgroup where supportive and preventive services might be focused.
Religiosity and quality of life: A dyadic perspective of individuals with dementia and their caregivers

Nagpal, N., Heid, A. R., Zarit, S. H., & Whitlatch, C. J. (2014). Aging & Mental Health, in press. We examine the effect of religiosity on well-being for individuals with dementia (IWDs). Findings suggest that religiosity of both the caregiver and the IWD affect perception of the IWD's quality of life. It is important that caregivers understand IWDs' values concerning religion as it may serve as a coping mechanism for dealing with dementia.

Health trajectories of family caregivers: Associations with care transitions and adult day service use

Liu, Y., Kim, K., & Zarit, S. H. (2014). Journal of Aging and Health, in press. The study examines family caregivers’ health changes over 1 year and the association of health trajectories with adult day service (ADS) use and caregiving transitions. Caregivers showed increasing functional limitations and decreasing bodily pain over time, whereas role limitation and general health perception remained stable. Caregivers’ trajectories of functional limitation were associated with their ADS use at baseline and their relatives’ placement. Findings underscore the potential health benefits of ADS use for family caregivers.

Social Inclusion, Relationships & Community Participation

Benefit finding and relationship quality in Parkinson’s disease: A pilot dyadic analysis of husbands and wives

Mavandadi, S., Dobkin, R., Mamikonyan, E., Sayers, S., Ten Have, T., & Weintraub, D. (2014). Journal of Family Psychology, 28(5), 728-734. This study examined the association between benefit finding and perceived marital quality between individuals with Parkinson’s disease (PD) and their partners. Perceiving positive consequences as a result of personally having PD or living with a spouse with PD is related to greater marital quality for both members of the marital dyad. Findings may inform individual and couples-based interventions that address the value of benefit finding and incorporate other techniques of positive reappraisal.

The experience of couples when one partner has a stroke at a young age: An interpretative phenomenological analysis

Quinn, K., Murray, C. D., & Malone, C. (2014). Disability and Rehabilitation, 36(20), 1670-1678. The consequences of stroke impact upon young stroke survivors and their partners and this study aimed to explore their joint experience. Three themes were identified: (1) Making sense of the stroke; (2) From partners to carer and “cared for”; (3) From partners to parent and child. The findings highlight the need for both partners to adapt to their relationship role changes and the importance of addressing the couple as a focus for intervention.
Person Centred Approaches / NDIS

What is a person-centred approach?: Familiarity and understanding of individualised funding amongst carers in New South Wales

Carers NSW surveyed carers of people with a disability to identify what they knew about person-centred approaches and how they felt about their introduction. Results indicate that there is a need to increase the willingness of carers to engage with person-centred approaches. Findings also indicate specific areas that need to be addressed in order to increase carers' awareness of these concepts and also to address existing negativity.

Preventing abuse of children and young people with disability under the National Disability Insurance Scheme: A brave new world?

This paper reviews evidence on abuse and neglect of children and young people with disability to help identify the nature of these risks and potential ways of thinking about and responding to these. The paper invites and challenges researchers, policymakers, and practitioners to engage critically with the knowledge already available and to question more deeply why abuse and neglect continue to diminish the lives of children and young people with disability.

Self-directed community services for older Australians: A stepped capacity-building approach

This paper reports on a self-directed care approach for older Australians with complex care needs. The evaluation suggests that while only a very small segment of older people is interested in a voucher or cash option, a substantially larger group would like to have greater say over and more direct access to their care, without, however, assuming administrative and financial responsibilities.

Ambiguity in practice? Carers' roles in personalised social care in England

This paper reports how dyads of older and learning disabled people with cognitive and/or communication impairments and their carers viewed the roles played by carers in personal budgets (PBs). Interviews indicated that carers played important roles in service users' assessments and support planning, but were less likely to report receiving assessments or support of their own. While carers had the potential to benefit from PBs and support arrangements for service users, this did not reflect practice that aimed to enhance choice and control for carers.
Developing the knowledge base about carers and personalisation: Contributions made by an exploration of carers' perspectives on personal budgets and the carer–service user relationship

This study aimed to explore the carer–service user relationship in the context of personal budgets. Although two thirds experienced negative feelings about having less involvement in the service user’s care, these feelings eased over time. Further analysis of these findings showed the study contributes not only to existing knowledge about the carer–service user relationship within personalisation but also to knowledge about the effects of personalisation on carers more generally.

CALD Carers

Language reversion among people with dementia from culturally and linguistically diverse backgrounds: The family experience

This paper presents the findings of a study of the experiences of family members of people with language reversion emanating from dementia. The study found that the presence of language reversion created additional challenges for family members of someone with dementia, particularly if the family member did not share the person's first language. Community-based aged care services have the potential to offer valuable support, but barriers of negative past experiences, lack of communication, stigma, cultural understanding, and locality need to be overcome.

The experience of family caregivers of older Korean Americans with dementia symptoms

This study examined the experience of dementia caregiving among Korean Americans. We identified eight themes: (a) struggling and overwhelmed, (b) keeping the cultural roles and responsibility; (c) doing it by themselves; (d) family as a source of stress; (e) limited knowledge and misconceptions; (f) learning as they go; (h) undiagnosed and misunderstanding medical care, and (i) barriers to using services and need of culturally responsive services.

Care-giving as a Canadian-Vietnamese tradition: ‘It's like eating, you just do it’

The objective of this study was to examine how Vietnamese family caregivers experience end-of-life care-giving for seriously ill family members. The ways in which care-giving was perceived and expressed are reflected in three themes: (i) Natural: identity and care work; (ii) Intentional: whole-person care; and (iii) Intensive: standards, struggle and the context of care.
Male Carers

Burden among male Alzheimer’s caregivers: Effects of distinct coping strategies


The purpose of this study was to identify the likelihood of male Alzheimer’s disease (AD) caregivers utilising coping strategies and to examine the effects of each coping strategy on caregiving burden. Implications suggest that emotion- and avoidance-focused coping among male AD caregivers may be maladaptive, that is, reinforcing burden. Male AD caregivers may benefit from more task-focused coping, such as planning and active problem solving.

Former Carers

Between worlds: The experiences and needs of former family carers


The purpose of this study was to explore the experiences and needs of former family carers in the post-caring/care transitions period. Post-caring was a transition that comprised themes that were represented as ‘loss of the caring world’, ‘living in loss’ and ‘moving on’ and symbolised as being ‘between worlds’. Transition was a complex interplay of emotions overlaid with economic and social concerns that had implications for their sense of health and well-being. This exploratory study begins to address the dearth of data on post-caring/care experiences, but further research is needed to inform support interventions to enable former family carers to ‘move on’.

Dyadic coping of parents after the death of a child


This article explores the grief process of parents following the death of a child due to a life-limiting illness, putting particular focus on dyadic coping. Aspects of common dyadic coping (e.g., sharing emotions, or maintaining bonds to the child) helped them work through their grief as a couple but also individually. We conclude that dyadic coping plays an important role in grief work and adjustment to bereavement.

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