RESEARCH SNAPSHOT

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

Early Intervention for Children with Hearing Loss: Information Parents Receive about Supporting Children’s Language


This study examined parents’ reports of information received from early intervention service providers about how to promote the language development of their children with hearing loss. The information parents receive is partially in line with current recommended practices, such as the importance of frequent communication with their children during everyday activities. However, parents also discussed the need for additional unbiased and specific information about how to promote their children’s language skills.

Family Quality of Life: A Key Outcome in Early Childhood Intervention Services—A Scoping Review


A study identified factors influencing the quality of life of families of children with disability. The review also explored the scales used to measure family quality of life (FQOL) as an outcome in early childhood intervention services (ECIS). Results were summarized as five factors that affect FQOL: disability-related support; family interactions/family relationships; overall well-being; support from services; and severity and type of disability.

The participation of parents of disabled children and young people in health and social care decisions


This study explored parents’ experiences of participating in decisions made with professionals about their disabled son or daughter’s care. Three themes emerged from the data: taking the lead, not knowing, and getting the balance right. Parents in this research recounted positive as well as negative experiences. Parents took on a protective role when decisions were made about their son or daughter and at times, reported the need to “fight” for their child.

Siblinghood through disability studies perspectives: diversifying discourse and knowledge about siblings with and without disabilities


This article suggests that a range of disability studies perspectives can usefully de-individualize and expand research about siblings where one has a disability. Through examples of how materialist, feminist and inclusive perspectives can be applied to open up research about siblings and disability, the article argues that viewing siblinghood through the range of disability studies perspectives has the potential to expand this research field and represent new facets of siblings’ identities and lives together.
**Intellectual Disability**

The roles of adult siblings in the lives of people with severe intellectual and developmental disabilities


This study considered the roles of adult siblings who have a brother or sister with severe intellectual and developmental disability (IDD). Several roles were identified, including caregiver, friend (social partner), advocate, legal representative, sibling (teacher/role model), leisure planner and informal service coordinator. Siblings assume key roles in the lives of people with IDD and need support from family and professionals to perform these roles.

**Self-compassion and psychological distress in parents of young people and adults with intellectual and developmental disabilities**


This study examines the association between self-compassion and measures of well-being for parents of adults with intellectual and developmental disabilities (IDD). Greater self-compassion was related to lower levels of stress and depression, even after accounting for other known stressors, such as economic disadvantage, having a child with an Autism Spectrum Disorder diagnosis, and high parent burden. Self-compassion may offer resiliency against these parenting challenges.

**Social anxiety and parental overprotection in young adults with and without intellectual disabilities**


This study examined whether peer relationships and parental overprotection are associated with social anxiety for people with intellectual disabilities. There were no significant differences in parental overprotection between groups, however, qualitative analyses revealed differences in experiences of social anxiety and parental overprotection. Further research into factors associated with social anxiety in people with intellectual disabilities may inform adaptations to therapies and early intervention.

**Autism Spectrum Disorder**

Emotionally Focused Couple Therapy for Parents Raising a Child with an Autism Spectrum Disorder: A Pilot Study


This study tested the effectiveness of Emotionally Focused Couple Therapy (EFT) with couples presenting with moderate to severe distress, who were also parents of a child diagnosed with an ASD. Results demonstrated significant decreases in marital distress at posttreatment and 6-month follow-up. The study also identified several unique themes associated with couple distress and the parenting experiences of this population.

Exploring Partner Intimacy among Couples Raising Children on the Autism Spectrum: A Grounded Theory Investigation


This study explored how couples raising children with autism spectrum disorder negotiate intimacy, including what contextual and temporal factors influence these processes. Results indicated that fostering intimacy in these couples’ relationships involves partners working together to make key cognitive and relational shifts. We also found that intimacy is not a fixed point at which couples one day arrive, but is an iterative process taking place over time and requiring work to develop and maintain.
“We will never be normal”: The Experience of Discovering a Partner Has Autism Spectrum Disorder


This study considered the experience of depression, distress, and trauma in the everyday lives of partners of individuals with Autism Spectrum Disorder (ASD), exacerbated during the time surrounding diagnosis. Six themes emerged, including: facing unique challenges within relationships; insisting partners seek diagnosis; initial shock and relief; losing hope for normalcy; making accommodations within relationships; and wishing for professional support.

Mental Health

Parents and carers of young people with mental ill-health: What factors mediate the effect of burden on stress?


This study examined whether, like carers of older people, parents and carers of young people with mental ill-health experience elevated levels of caregiver burden and stress. Strategies aimed at increasing awareness of the impact of activity restriction and encouraging parents and carers to find ways to maintain essential activity may reduce stress, improving mental health and well-being in parents and carers.

Relational recovery: beyond individualism in the recovery approach


This paper outlines the shortcomings of individualistic approaches to recovery from mental illness, and explores the alternative notion of relational recovery. Interpersonal relationships can more accurately be seen as suffusing all aspects of recovery, including experiences such as hope, identity and empowerment. We conclude by arguing that the way forward for mental health systems lies in developing, promoting and implementing approaches that properly acknowledge the irreducibly relational nature of recovery.

Comparing the Effect of a Moderate Physical Activity Intervention on the Mental Health Outcomes of African American and Caucasian Dementia Family Caregivers: A Secondary Data Analysis


This study considers a randomized controlled trial that tested a 12-month moderate physical activity intervention to improve the mental health of dementia caregivers. Findings suggest that the mental health needs of African American caregivers warrant additional exploration, where physical activity may be of benefit. These findings provide a cultural perspective to consider during intervention development for future nurse-driven research.

Caregiver burden and correlates among caregivers of children and adolescents with psychiatric morbidity: a descriptive cross sectional study


This study explores caregiver burden among caregivers of children and adolescents with psychiatric morbidity. Caregivers of children and adolescents with psychiatric morbidity suffer high levels of caregiver burden. A multidisciplinary approach to management of children with psychiatric morbidity to address challenges faced by the caregivers may alleviate the burden; thereby improving clinical outcomes of children and adolescents with psychiatric morbidity.
Challenges experienced by parents living with a child with attention deficit hyperactivity disorder


Explores parents’ experiences of living with a child with attention deficit hyperactivity disorder (ADHD). Five themes emerged: burden of care; emotional effects; social effects; impact of educational challenges, attempts to cope with burden of care. Parents experience burdensome emotions and impaired social and occupational functioning. Health care practitioners need to take note of the challenges inherent to parenting a child with ADHD in order to provide multi-disciplinary interventions aimed at empowering and supporting parents.

Serious Illness / Chronic Condition

Parents’ early healthcare transition experiences with preterm and acutely ill infants: a scoping review


The objective of this review was to map and synthesize evidence on the experiences and needs of parents of preterm or ill infants as they transition within and between healthcare settings following birth. Four key themes were identified: parent distress throughout transition, parenting at a distance, sources of stress, and of support. Opportunities to improve parents’ early transition experiences include enhanced engagement, communication, information-sharing and shared decision-making between health care providers and parents.

Multiple Chronic Conditions in Spousal Caregivers of Older Adults With Functional Disability: Associations With Caregiving Difficulties and Gains


Multiple chronic conditions (MCCs) are common and have harmful consequences in later life. Along with managing their own health, many aging adults care for an impaired partner. This study examined three categories of MCCs based on similarity of management strategies and their associations with caregiving difficulties and gains. Spousal caregivers with MCCs involving discordant management strategies appear to be at risk for adverse care-related outcomes and may benefit from support in maintaining their own health.

The support needs of parents having a child with a chronic kidney disease: a focus group study


This study describes parents’ support needs regarding the problems they experience in having a child with chronic kidney disease (CKD). Needs regarding balancing their personal life are seldom prioritized by parents as the child's needs are considered more important. Therefore, it is important that healthcare professionals should not only attend to the abilities of parents concerning their child's disease management, but also focus on the parents’ abilities in balancing their responsibilities as a caregiver with their own personal life.

Aged & Dementia

A review of couple-centred interventions in dementia: Exploring the what and why – Part A

Bielsten, T. and I. Hellström Dementia 0(0)

This review explored the ‘what’ and ‘why’ of interventions aimed at couples where one partner has a diagnosis of dementia and in which the couple jointly participate. The findings of this review indicate that joint interventions for people with dementia and care partners are lacking a genuine dyadic approach where both partners’ views of their relationship are valued. In order to identify targets for support and to use the appropriate outcome measures, the quality of the relationship should be recognised and taken into account.
An extended review of couple-centred interventions in dementia: Exploring the what and why — Part B

Bielsten, T. and I. Hellström. Dementia 0(0)

This scoping review is an extended version of a narrative review of couple-centred interventions in dementia shared in Part A and the previous publication in this edition. The rationale for expanding Part A emerged through the fact that most dyadic interventions have samples consisting of a majority of couples. The aim of this second review is to explore the ‘what’ (types of interventions) and the ‘why’ (objectives and outcome measures) of dyadic interventions.

The lived experiences of dementia in married couple relationships

Clark, S., et al. Dementia 0(0)

This study explored the dyadic perspective of dementia within a couple relationship. Analysis revealed three themes: maintaining a bond, change and adjustment, and the challenge of coping. The results highlight the importance of studying the dyadic perspective and including people with dementia in research. Couples experienced an enduring commitment to one another as they adjusted to life with dementia.

Development of “down the road”: An interactive toolkit about driving cessation for dementia caregivers


This paper details the development of a toolkit called Down the Road, designed to aid dementia caregivers in the driving cessation process. Down the Road incorporates the expressed needs of dementia caregivers to translate knowledge into an effective, research-based toolkit that can provide caregivers with an interactive resource for use individually or in facilitated groups.

An exploration of the experience of using calendar reminders for people with dementia and family carers

Evans, N. and L. Collier Dementia 0(0)

This study examines the experience and practicalities of using calendar reminders from the perspective of people with dementia and family carers. Findings suggest that calendars are used either intensively as external memory records or more casually and randomly for reassurance. The familiarity and location of the calendar and its utility to the person with dementia and carer, all contribute to its efficacy. For carers the experience of supporting calendar reminders encompasses practical, cognitive and emotional effort.

Review of studies on spousal caregivers of frail spouses in South Korea

Oh, Y. and E. Han, International Social Work 0(0)

This study aimed to review and critique the empirical literature on dyadic problems of spousal carers. Four major results were identified: assuming caregiving roles easily caused various caregiving-related problems, such as stress and burden; care recipients’ health conditions and problems were one of the crucial factors influencing caregiving-related problems in spousal carers; caregiving easily caused marital problems in couples with frail spouses; and spousal carers had negative communications with their care recipients.

Recognition & Support of Carers

The American Care Landscape: Challenges and Solutions for the 21st Century


Finding quality care was very important. We found an excellent program, but it cost $70 per day. With my reduced hours at work, this was a strain—but we had to keep her safe and well cared for. I put off paying down my student debt or saving any money. Less than a year later, I was laid off.
Peer support for families of children with complex needs: Development and dissemination of a best practice toolkit


This paper describes the key activities used to develop and disseminate the Peer Support Best Practice Toolkit. The toolkit is freely available online and is structured into four sections: background and models of peer support, case studies of programs, resources, and rapid evidence review. The toolkit format was valuable to synthesize and share best practices in peer support. Strengths of the work include the integrated approach used to develop the toolkit and the inclusion of published research literature and experiential evidence.

Carer Health & Wellbeing

“What Hath Night to Do with Sleep?”: The Caregiving Context and Dementia Caregivers’ Nighttime Awakenings


This study examined care receiver and caregiver contextual factors, caregiver health and psychological wellbeing as predictors of caregivers’ nighttime awakenings. Emotional caregiving difficulties were associated with nighttime awakenings even accounting for caregivers’ health and care receivers’ disability. Thus, interventions improving caregiver distress may improve sleep health. Clinicians should screen caregivers for nighttime awakenings so that evidence-based interventions and treatments can be implemented.

Social Inclusion, Relationships & Community Participation

Parent-child interactions and children with cerebral palsy: An exploratory study investigating emotional availability, functional ability, and parent distress


This study investigated links between parent–child emotional availability and both child functional abilities and parent distress in a sample of parents and children with cerebral palsy. Findings from this study are consistent with the wider literature showing a link between parental depression and the parent–child relationship and extend this link to the cerebral palsy population. The importance of routine screening for parental mental health problems in early childhood intervention is highlighted by these findings.

The mediating effect of neighbour relationship between community social support and elderly’s subjective well-being in China

Jiang, S., et al. Journal of Health Psychology 0(0)

This study investigated the relationship between community social support, neighbour relationship, and the subjective well-being of the elderly in China. Results showed that community social support could indirectly affect the subjective well-being of the elderly through the complete mediating effect of neighbour relationship, although there was no significant correlation between community social support and the elderly’s subjective well-being. Implications for theory, social work, and social policy were discussed.

Rural

The housing pathways of single older non-home owning women in a rural region of Australia


This paper reports on empirical, qualitative research conducted in a rural region of Northern New South Wales, Australia. Using a Feminist Standpoint approach, this paper examines the housing pathways in relation to the current circumstances of single, older, non-home owning rural/regional women who live independently. We attempt to show how these women have been caught in the crosshairs of changing cultural norms which may still be current in rural/regional Australia.
**Young Carers**

**‘This is killing me inside’: The impact of having a parent with young-onset dementia**

*Aslett, H. J., et al. Dementia, 0.*

Explored the experience of young adults with a parent with young-onset dementia. Participants experienced a number of stresses relating to their parent’s illness. Five themes were found: relationship changes, shifts in roles and responsibilities, support for non-affected parent, support for self and the impact of living with their own potential risk of dementia. Findings suggest that individuals with a parent with young-onset dementia have needs which service providers should consider in the wider context of young-onset dementia care.

**‘I couldn’t just entirely be her sister’: the relational and social policy implications of care between young adult siblings with and without disabilities**


This article explores how young adult siblings with and without disabilities perceive, talk and act with regard to the different types of care enacted between them. During young adulthood, some types of care can endanger siblings’ capacity to feel like siblings and discusses ways that young adult siblings talk and act in order to keep their role within the bounds of a normative sibling relationship. Implications for social policy are discussed, particularly with regard to seeing siblings of people with disabilities as young carers.

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