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).

Physical Disability

Parenting intervention combined with Acceptance and Commitment Therapy: A trial with families of children with cerebral palsy


This study aims to examine the effects of Stepping Stones Triple P and Acceptance and Commitment Therapy on child functioning, quality of life, and parental adjustment. Participants showed increased functional performance and quality of life as well as decreased parental psychological symptoms. No differences were found for parental confidence. This intervention may effectively target child functioning, quality of life, and parental adjustment.

Child characteristics, caregiver characteristics, and environmental factors affecting the quality of life of caregivers of children with cerebral palsy


Investigates the determinants of the quality of life of caregivers of children with cerebral palsy based on the International Classification of Functioning, Disability and Health for Children and Youth. Knowledge of the determinants of QOL could serve as a guide in a holistic approach to evaluation and intervention and help plan interventions targeted at these determinants to improve the QOL of caregivers of children with CP.
Intellectual Disability

Fathers of children with or without ID: Understanding long-term psychological symptoms


The purpose of this study was to understand how reports of child behaviour problems, along with spousal support related to parenting tasks, associated with fathers' reports of psychological symptoms. Child behaviour problems are more important than disability status in predicting father's psychological symptoms. Spousal support predicts paternal psychological symptoms and can be viewed as an additional resource for fathers.

The importance of emotions: The socialisation of emotion in parents of children with autism spectrum disorder


In this study, we compared the emotion socialisation practices of parents of children with ASD and to those of parents of children that are typically developing. Analysis revealed significant differences in responses to anger and fear. These results demonstrate a need for research examining the relationship between, and moderators of, parents' emotional reactions and the development of emotional competence in children with ASD.

Spilling over: Partner parenting stress as a predictor of family cohesion in parents of adolescents with developmental disabilities


Investigates cohesion in families of adolescents with developmental disabilities, particularly with respect to partner stress. Above other factors, greater partner stress predicted poorer family cohesion for both fathers and mothers. To improve the overall climate of families, care providers should consider individual relationships. Family-centred practices are likely to lead to greater feelings of cohesion and overall better individual and family well-being.
**Mental Health**

**Pediatric SCI/D caregiver mental health and family dynamics in Colombia, South America**


Examines the connections between family dynamics and mental health of caregivers of youth with spinal cord injuries/disorders from Colombia. It was hypothesized that lower family functioning would be associated with poorer caregiver mental health. Family dynamics were not significantly associated with caregiver depression. Family satisfaction was the only family dynamics variable to yield a significant unique association with caregiver mental health.

**Tangible needs and external stressors faced by Chinese American families with a member having schizophrenia**


Examines the needs and stressors experienced by Chinese American families with a member living with schizophrenia. Families expressed concerns regarding housing, finance, work, study, and the shortage of bilingual psychosocial services. Interacting with government offices and social services agencies caused anxiety and frustration. Participants had needs for language translation, knowledge about resources, and advocacy by case managers.

**Drug/Alcohol Dependency**

**Impact of mid-life symptoms of alcoholism on the health and wellbeing of aging parents of adults with disabilities**


The study examined the effect of adult children’s disability on parents' physical health in later life and the extent to which parents' symptoms of alcoholism in mid-life moderates the link between children's disability and later life parental health. Results showed that the negative health consequences in later life of having a child with a developmental disability were greater for those who showed more symptoms of alcoholism in mid-life.
Serious/Terminal Illness

“Care that matters”: Family-centred care, caregiving burden, and adaptation in parents of children with cancer
Aims to identify the direct and indirect associations between family-centred care and adaptation outcomes specifically in the context of pediatric cancer, through caregiving burden, between parents’ FCC and quality of life and life satisfaction. The way parents perceive formal care, as being more or less family-centred, may influence the burden they experience as caregivers of a child with cancer and, indirectly, their adaptation.

Desirable information of opioids for families of patients with terminal cancer: The bereaved family members’ experiences and recommendations
This study aims to clarify the state of information regarding opioids for families and what kinds of experiences they had with opioids while the patient was followed as an outpatient and inpatient. It concludes that it is important for families of patients with cancer to be explained profound and careful information of opioid.

“He’s on his dying bed”: Next-of-kin’s experiences of the dying body
This study looks at family members of dying patients who have grown accustomed to providing daily body care and the transition from home to hospital. Themes of social disorganization and a loss of control over the body emerged. Next-of-kin experienced the physical and functional breakdown of their loved one’s body. Understanding the nature of the loss of control may help alleviate the strain on families.

End-of-life decision-making for children with severe developmental disabilities: The parental perspective
Aims to understand how parents of children with severe developmental disorders experience their involvement in end-of-life decision-making, how they prefer to be involved and what factors influence their decisions. Most parents wish to actively share in the end-of-life decision-making process. An important emerging factor in this process is parents’ feeling they have to stand up for their child's interests in conversations with the medical team.
Aged & Dementia

Illness representations in caregivers of people with dementia

The aim of this study is to explore components of illness representations (label, cause, control and timeline) in caregivers of people with dementia. The extent of uncertainty about the cause, timeline and controllability of dementia indicated that caregivers need information on these areas.

Exploring the benefits of respite services to family caregivers: Methodological issues and current findings

This study identifies problems associated with the usual research approaches for studying respite care, with the goal of stimulating use of novel and more appropriate research designs that can lead to improved studies of community-based services. An emphasis on Randomised Controlled Trials by funders and researchers is not supported by scientific evidence. Alternative designs can lead to development of a valid body of research.

Caregiver burden in family carers of people with dementia with Lewy bodies and Alzheimer's disease

Characterises the differences in caregiver distress between carers of people diagnosed with dementia with Lewy bodies and people with Alzheimer's disease, with a view to differentiate and improve support for caregivers. Caregiver distress differed between people caring for someone with AD and those caring for someone with DLB. Findings have direct implications for the needs and resources available for these individuals.

An evaluation of Cognitive Stimulation Therapy sessions for people with dementia and a concomitant support group for their carers

Ascertained the impact of Cognitive Stimulation Therapy on the cognitive function of people living with dementia and whether attending a concomitant carer support group was beneficial to carers. Cognitive Stimulation Therapy had some, especially social, benefits for people living with dementia. Attending the carers support group was beneficial for them in terms of gaining a better understanding of dementia, developing coping skills and having peer support.
Stroke/TBI

Life satisfaction and strain among informal caregivers of patients with traumatic brain injury in Malaysia


Aims to determine the life satisfaction and strain on informal caregivers when caring for traumatic brain injury patients and to examine the factors predicting the level of strain among the informal caregivers. Caregivers with lower monthly income and caring for TBI patients with cognitive and neuro-behavioural disturbances are at higher risk of developing strain. Rehabilitation interventions post-discharge should aim to support caregivers at risk.

Recognition & Support of Carers

To care or not to care: a narrative on experiencing caring responsibilities


This paper explores caring responsibilities in everyday life by a thorough investigation of the lived experience of one woman, called Eva. Her narrative shows that for her, caring requires a relationship in which moral intimacy can be experienced. Therefore, caring responsibilities rather inflict ambiguous personal struggling about reciprocity, vulnerability and openness in her relationships than about tension between care for herself and care for the other.

Carer Health & Wellbeing

Evaluating the effects of mindfulness-based interventions for informal palliative caregivers: A systematic literature review


Aims to describe, evaluate and synthesise the peer-reviewed literature on the effects of mindfulness-based interventions for informal palliative caregivers. Results suggest both feasibility and potential benefit. Further research is required to explore the outcomes identified by informal caregivers, as the reduced magnitude of effect may suggest that we are not measuring the right outcomes in this context.
Person Centred Approaches / NDIS

Understanding effects of flexible spending accounts on people with disabilities: The case of a consumer-directed care program


This study explores the saving behaviour, barriers, and facilitators along with effects of participating in a consumer-directed care program among people with disabilities. Results suggest respondents saved money through the program to enable them to purchase goods and services they needed to enhance their welfare and quality of life. Items saved for fell in 3 broad categories: household equipment, individual functioning, and home modification.

CALD Carers

The human dimensions of post-stroke homecare: Experiences of older carers from diverse ethnic groups


This paper explores both the experiences of carers in black and minority ethnic groups, whose relative was receiving social care services in their own home after a stroke and the value of a theory of humanising care to understand and explain these experiences. Five interacting themes emerged: communication and bureaucracy; time and timing; communication and rapport building; trust and safety; humanity and the human dimensions of care.

Culturally competent social work practice with Chinese and Korean family caregivers of older adults: Perspectives from the field


This study examined caregiver programs that reduce caregiver stress, improve family quality of life, strengthen coping skills and alleviate strain on health, and the effectiveness of these services. Information is collected from the perspective of direct service professionals and considers if such programs could be improved by tailoring services to address cultural competency.

Disclaimer

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