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 functioning and behaviour problems in children with Autism Spectrum Disorders: The mediating role of parent mental health

This study explored the relationship between child behaviour problems and family functioning in families where there was a pre-schooler with an Autism Spectrum Disorder (ASD). The relationship between child behaviour problems and family functioning was mediated by depressive symptoms, but not stress and fatigue, suggesting that when parents are overburdened by behaviour problems, there are implications for the family.

Division of labor in families of children and adolescents with autism spectrum disorder

This study examined the division of labour and its relation to parenting stress and marital adjustment in married couples who have a child with ASD. Overall, couples demonstrated a pattern of partial role specialisation in which mothers engaged in more child care and fathers engaged in more paid employment. Time spent in paid employment and satisfaction with the time that one's spouse spent in child care had important associations with parenting stress and marital adjustment.
Choice and caring: The experiences of parents supporting young people with Autistic Spectrum Conditions as they move into adulthood

This paper reports findings about parents' experiences of caring for young people with Autistic Spectrum Conditions (ASCs) moving into adulthood. In the perceived absence of service support, parents acted as ‘care-coordinators’ and ‘life-supporters’ for their child. These roles came with little choice, emotional demands and personal restrictions.

The experience of Singaporean caregivers with a child diagnosed with autism spectrum disorder and challenging behaviours

This study presents an analysis of the experience of caregivers with a child diagnosed with autism spectrum disorder who exhibits challenging behaviours. Two dominant themes emerged: sense of responsibility and renewed appreciation of self. Through coordinating actions with their child, spouse and social relations, over time the caregivers developed a deeper appreciation of their personal strengths and resourcefulness.

Mental Health

“How can I take a break?” Coping strategies and support needs of mental health carers

This study surveyed carers from across New South Wales and found that carers of people with mental health issues reported poorer health and mental health themselves than any other group of carers, despite being more likely to access supportive services. The effectiveness of personal coping strategies employed by mental health carers is also discussed. Results raise implications regarding the support of mental health carers and their subjective wellbeing.

Caring for someone with depression: Attitudes and clinical practices of Australian mental health workers

Australian mental health workers completed a questionnaire to investigate their attitudes towards, barriers experienced and current clinical practices when working with carers of people with depression. Attitudes and barriers were associated with the inclusive clinical practice of participants who worked with mental health consumers, but not participants who worked with family members and carers. Further research should explore not only what inhibits but also what enables the participation of family members and carers in the care and treatment process for people with depression.
Youth and caregiver access to peer advocates and satisfaction with mental health services

This study examines associations between reported access to a youth or family advocate and perceptions of satisfaction with mental health services. A greater proportion of youth or caregivers with access to peer advocates compared to those without access responded positively on the satisfaction domains of access to services, appropriateness of services, participation in services and overall satisfaction. Access to peer advocates was also positively associated with social connectedness for caregivers compared to those without access.

Serious/Terminal Illness

Health care professionals’ perspectives of the experiences of family caregivers during in-patient cancer care

This study describes cancer care health professionals’ perceptions of family members who served as family caregivers (FCs) and their need for support during the in-hospital cancer treatment of their ill family member. Four main themes describe health professionals’ perceptions of FCs: an asset and additional burden, infinitely strong and struggling with helplessness, being an outsider in the centre of care, and being in different temporalities. System changes are needed in health care, so that the patient/FC dyad is viewed as a unit of care, which would enable FCs to be given space and inclusion in care, with their own needs simultaneously considered alongside those of the patient.

Strategies to support spirituality in health care communication: A home hospice cancer caregiver case study

Using a home hospice nurse visit immediately following the death of a patient as a case-study, we identify spiritually-sensitive communication strategies. The nurse incorporates spirituality in her support of the family by 1) creating space to allow for the expression of emotions and spiritual beliefs and 2) encouraging meaning-based coping, including emphasising the caregivers’ strengths and reframing negative experiences.
Aged & Dementia

Providing information for family carers of hospital patients experiencing dementia

This project involved preparing nurses to initiate a dialogue with family carers of patients diagnosed with dementia, developing a protocol to guide the nurses as they provided carers with a dementia information booklet, and obtaining feedback from the nurses using a questionnaire. Recommendations are to embed this strategy into nursing practice, keep the staff informed, and ensure that the booklet is kept in a location visible to the staff.

The experience of family carers of people with dementia who are hospitalised

Hospital admission of a person with dementia can have a significant impact on the family carer, who temporarily relinquishes caring to health professionals. Adjusting to the change in the carer’s role can be challenging and result in feelings of helplessness, loneliness, loss of control and being undervalued. The carer should be included in decision-making as the 'expert' in the care of the person with dementia. The carer and the patient must be considered as a dyad in relation to discharge planning.

What carers and family said about music therapy on behaviours of older people with dementia in residential aged care

This study sought to evaluate the effectiveness of group music therapy (MT) intervention on behaviours of older people with dementia. Care providers and family members acknowledge the instrumental value of MT and its helping with cognition and exercise.

What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study

We aimed to assess whether spousal dementia carers can achieve resilience and to highlight which assets and resources they draw on to facilitate or hinder resilience, using an ecological framework. A resilient carer was characterised as someone who stays positive and actively maintained their relationship and loved one’s former self. Resilient carers were knowledgeable and well supported by family but especially friends, with whom they shared this knowledge. They were more actively engaged with services such as respite care.
‘Singing for the Brain’: A qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers

Osman, S. E., Tischler, V., & Schneider, J. (2014). Dementia, in press.
This study explored the impact of Singing for the Brain™, an intervention based on group singing activities for people with dementia and their carers. Social inclusiveness and improvements in relationships, memory and mood were found to be especially important to participants. As well as enjoying the sessions, participants found that attending Singing for the Brain™ helped in accepting and coping with dementia.

Recognition & Support of Carers

Implications of Smart Wear technology for family caregiving relationships: Focus group perceptions

Recent and future development of Smart Wear technology (devices integrated into clothing that monitor care-recipients) might assist family caregivers with tasks related to caring for young children, relatives with disabilities, and frail spouses or parents. Focus group interviews of family caregivers were conducted to explore perspectives regarding the potential integration of Smart Wear technology into their family caregiving. Three major themes emerged: quality and quantity of interaction, boundary issues, and implications for anxiety.

Shared decision-making in dementia: A review of patient and family carer involvement

This paper reviews findings concerning the decision-making process of persons with dementia and their family carers, with a particular focus on the extent and determinants of involvement of persons with dementia in the decision-making process. Results indicated that not all persons with dementia are excluded from participating in the decision-making process, but there is a broad spectrum of what constitutes shared decision-making in dementia. Studies concerning the determinants of shared decision-making mostly focused on non-modifiable factors. Future research is needed to better promote shared decision-making among persons with dementia and their family carers.
**Carer Health & Wellbeing**

**Caregiver distress in dementia in rural Victoria**


The aim of this study was to explore the levels of stress, anxiety and depression of informal carers caring for someone with dementia in a rural setting. Almost half of the respondents reported levels of stress and depression in the moderate to severe range. Behavioural and psychological symptoms of dementia exhibited by care recipients were associated with the level of stress reported by the carer.

**Incongruence between stroke survivor and spouse perceptions of survivor functioning and effects on spouse mental health: A mixed-methods pilot study**


This study investigated stroke survivors' and caregiving spouses' individual perspectives on survivor cognitive and physical functioning and the extent to which incongruence between partners' perceptions affects spouse depressive symptoms and overall mental health. Spouses rated survivor cognitive functioning as significantly worse than survivors rated their own. Partner incongruence has an impact on spouse depressive symptoms and overall mental health. Interventions focused on improving communication between partners about survivor abilities may be effective for improving the mental health of spousal caregivers.

**Social Inclusion, Relationships & Community Participation**

**The importance of reciprocity for female caregivers in a super-aged society: A qualitative journalistic approach**


Our aim was to describe the observations and thoughts of one woman's experience of living with her elderly parents. The case was a single woman in her late 40s living with her aged parents. Reciprocity was identified as the glue holding the joy and burdens of the role of caregiving for elderly parents. Moreover, gender was identified as a motivator for reciprocity from a macro to a micro level in a super-aged society.
Indigenous Australians and the National Disability Insurance Scheme


The Australian Government is in the process of developing a National Disability Insurance Scheme (NDIS) for Australia. As this monograph was written before the initial launch of NDIS, it contains no discussion of the launch sites or their evaluation. The best available data suggests that the Indigenous population experiences profound or severe core activity limitations at more than double the rate of non-Indigenous Australians. These higher rates of disability mean that the NDIS is likely to be of significant benefit to Indigenous Australians. Not only are rates of disability higher for Indigenous Australians, but many Indigenous people also face significant barriers to accessing disability planning and support services. The first part of this monograph aims to identify and assess the range of disability service delivery models available in order to overcome the barriers to accessing disability support services experienced by Indigenous Australians. The second part analyses existing data sets to ascertain the extent and nature of disability in the Indigenous population. The work is intended to inform future policy development of a national scheme, and thereby assist Indigenous Australians in accessing support services appropriate to their cultural and geographic needs; sharing in opportunities available to the general Australian population; and participating fully in the economic and social life of their community.

Public health policy and social support for immigrant mothers raising disabled children in Canada


A literature review regarding the social support of immigrant mothers of disabled children in Canada was undertaken with a focus on settings where supports need to be shored up. Immigrant mothers experience numerous barriers to social supports for themselves and their disabled children. There are negative impacts on maternal health as a result of inadequate policy offerings. Public health policy needs to be refashioned in light of weak systems and supports for both immigrant mothers and disabled children and to acknowledge that the current system poses concerning implications for the long-term health of both groups.
Young Carers

“It’d be nice if someone asked me how I was doing. Like, ‘cause I will have an answer”: Exploring support needs of young carers of a parent with Huntington’s disease

Kavanaugh, M. S., Noh, H., & Studer, L. (2014). Vulnerable Children and Youth Studies, in press. This study explores the support needs of children and adolescents aged 12-20, who provide care to a parent with Huntington’s disease (HD). Data analysis elicited three main categories associated with support needs: (1) instrumental support, (2) emotional support, and (3) personal needs. Each category detailed the need for friends to be understanding, others to show care for the caregiver and for the young carers to receive assistance with caregiving tasks. Furthermore, they stated a need for information and advice about caregiving, and the creation of outlets, such as support groups, to help them feel less alone and to normalise their situation. With little information on HD and minimal support outlets, many study participants lack resources, which exacerbates their isolation and vulnerability to negative impacts of caregiving. Thus, the results of this study provide clear implications for social work and health care professionals in designing support programs and services targeted to young carers of a parent with HD.

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