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

**Improving policy and practice: Adults with intellectual disabilities and their families**


The article discusses the unintended consequences of two concurrent and successful policy responses: carer policy and disability rights policy. By describing key elements of these policies and identifying points of conflict arising from the separate policy pathways, it is concluded that integration of the perspectives of people with intellectual disabilities and those of their family members can improve policy and service responses.

**When families relinquish care of a child with a disability: Perceptions from birthmothers**


This paper explores the experiences of mothers who relinquished care of their child with a disability to residential care in the child protection system in Queensland. The mothers' narratives put into sharp focus the socio-political nature of caring for a person with a disability, and the need for more coordinated resources and expertise in supporting such families. According to the mothers’ perspectives, relinquishment provided some reprieve from daily caring responsibilities but was complicated by associated feelings of grief, anxiety, and guilt; behavioural and emotional adjustment of the child with a disability; and difficulties working collaboratively with child protection workers.
Cognitive aging in parents of children with disabilities


This study examined whether there is an evidence of accelerated cognitive aging among parents of children with disabilities. The results show that parenting children with disabilities over a prolonged period of time jeopardizes cognitive function (especially memory) among older mothers, possibly via the mechanism of heightened parenting stress.

Women who sacrifice themselves for everybody: Qualitative research with mothers of disabled children


This study examined the experiences of women whose children with cerebral palsy received a treatment at a physiotherapy and rehabilitation centre. The findings of the study were interpreted under four main themes: the lives of the women after their disabled children were born; being a woman within family life, participation in decision-making, and domestic division of labour; participation in public life and relations with women's associations; the self-sacrifice; and the self-realization within the scope of self-concept.

Enhancing the resilience of parents of adults with intellectual disabilities through volunteering: An exploratory study


This study investigated the relationships between participation in a volunteer program and the resilience protective factors of parents. The results showed that participants achieved positive changes in social resources and meaning of life after joining the volunteer program.

Families' experiences of seeking out-of-home accommodation for their adult child with an intellectual disability


This study examined the process of seeking out-of-home accommodation for an adult son or daughter with intellectual disability. Parents' aging and increased health problems along with the offspring's wish for greater independence were the main reasons for seeking out-of-home accommodation. Findings showed that families experienced seeking housing as stressful and frustrating and would like to see social care and housing professionals acknowledge them as collaborative partners in the process.
Mental Health

Family experiences of living with an eating disorder: A narrative analysis
This study explores the experiences of an elite triathlete with an eating disorder in conjunction with the experiences of her parents. Family difficulties arose when personal experiences strayed from culturally dominant narrative forms and when family members held contrasting narrative preferences. Suggestions are forwarded as to how an appreciation of eating disorder illness narratives might inform treatment and support.

The significance of services in a psychiatric hospital for family members of persons with mental illness
We examined the significance to family members of the services they received from the Family Members’ Support and Consultation (FMSC) service centre. The participants emphasised the significance of the immediacy and accessibility of support provided, as well as the positive effects of systemic interventions aimed at changing the relationships between family members and systems in the psychiatric hospital. Our findings show the importance of integrating a service that focuses on the needs of family members of persons with mental illness within a psychiatric hospital.

Horses for courses? A qualitative exploration of goals formulated in mental health settings by young people, parents, and clinicians
This research sought to explore goals set by children and young people, parents/caregivers and jointly by a combination of children/young people, parents/caregivers and/or clinicians within mental health settings. Most commonly rated goals from children focused on coping with specific difficulties, personal growth and independence. Parent goals focused mainly on managing specific difficulties, parent-specific goals and improving self or life. Jointly negotiated goals focused on parent-specific goals, self-confidence and understanding, hopes for the future and managing specific problems. The results suggest that goals may capture areas not captured by other normed outcome measures.
Nurses' experience of maintaining their therapeutic relationship with outpatients with bipolar disorder and their caregivers during different stages of a manic episode: A qualitative study


The purpose of this study was to determine nurses' experiences of their therapeutic relationship and nursing interventions to outpatients and caregivers during different stages of mania. Nurses experienced dual loyalty when facing conflicting interests. They strived to stay connected to patients and caregivers with an open and nonjudgmental attitude. Early involvement of caregivers in the treatment is recommended.

Drug/Alcohol Dependency

What is it like to be the wife of an addicted man in Iran? A qualitative study


This study is the first to explore in detail the impact on spouses of addicted men in Iran. Present findings confirm the conclusions of similar research conducted in other countries, that substance misuse in the family can have devastating effects for spouses, on children and all aspects of family life. The situation for Iranian wives may be compounded by the relatively closed nature of family life, and the existence of culturally based attitudes, including shame, towards “family defects” such as addiction.

Chronic Condition

Families living with chronic illness: Beliefs about illness, family, and health care


The aim of this study was to illuminate illness beliefs of families living with chronic illness. Illness beliefs have importance for how families respond to and manage situations that arise from their encounters with illness. Nurses have to make space for and listen to families’ stories of illness to become aware of what beliefs may support and encourage family well-being and healing. The Illness Beliefs Model provides a touchstone whereby nurses can distinguish both individual and shared beliefs within families living with chronic illness and provide ideas for family intervention if needed.
Serious/Terminal Illness

**Dyadic coping within couples dealing with breast cancer: A longitudinal, population-based study**


This study examined whether the supportive, delegated and negative dyadic coping provided by patients and partners and their common dyadic coping as a couple were associated with change in relationship quality and depressive symptoms over time. The more patients rated the couple as engaging in common dyadic coping, the higher relationship quality and the fewer depressive symptoms both patients and partners experienced. Partners experienced fewer depressive symptoms the more delegated coping they provided to the patient, but more depressive symptoms the more supportive coping the patient provided to them.

**Needs of caregivers in heart failure management: A qualitative study**


This study identified the needs of caregivers supporting a person with heart failure to inform the development of a caregiver resource to be used as part of a home-based self-management programme. Caregivers identified needs about supporting management of heart failure. Secondly, as they make the transition to becoming a caregiver, they need to develop skills to undertake difficult discussions about the role. Thirdly, caregivers require skills to engage social support, and voluntary and formal services while recognising that the long-term future is uncertain.

**Family rituals and quality of life in children with cancer and their parents: The role of family cohesion and hope**


This article explores the role of family cohesion and hope as mediators of this association in children with cancer and their parents. When children and parents reported higher levels of family rituals, they also reported more family cohesion and hope, which were linked to better quality of life (QoL). Family rituals are important in promoting QoL in paediatric cancer via family cohesion and hope individually and via family cohesion in terms of parent–child interactions.
Conceptualising psychological distress in families in palliative care: Findings from a systematic review

This article ascertains how psychological distress is conceptualised in families receiving palliative care. This review proposes that distress in families in palliative care can be conceptualised and illustrated within a tiered model of distress. Further research is merited to advance current explanatory frameworks and theoretical models of distress.

Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: A discrete choice experiment

This study quantified willingness to pay of patients with advanced cancer and their caregivers to extend the patients’ life by 1 year and other end-of-life improvements. Consistent with our hypothesis, caregivers had a greater willingness to pay than patients to extend life and for most other end-of-life improvements. Differences in willingness to pay of patients and caregivers suggest the need for eliciting patient preferences during treatment decision making as opposed to relying on caregiver input.

Aged & Dementia

Family caregivers’ experiences of caring for a relative with younger onset dementia: A qualitative systematic review

This article presents findings of a systematic review exploring the experiences of family caregivers of persons with younger onset dementia. The review findings support increasing evidence that despite the stress of caring for a person with dementia damage, family members have the capacity to cope, adapt, and grow through their experiences.

Satisfaction with the relationship from the perspectives of family caregivers, older adults and their home care workers

This study evaluated satisfaction with the relationship from the perspectives of the three members that make up the home caregiving triad: older adults, their family members and their home care workers. The study highlights the importance of studying satisfaction with the relationship in the home care setting and calls for further examination of the entire caregiving triad. The home care worker plays a key role in ensuring the overall satisfaction in the caregiving triad.
here:now – Conceptual model of the impact of an experiential arts program on persons with dementia and their care partners

This is an analysis of here:now, a joint arts engagement program for persons with dementia and their care partners that involves gallery tours and art classes. The program was well received by both persons with dementia and care partners as evidenced by high levels of engagement, mindfulness, social connection, and positive interactions. Results form the basis for a conceptual model for assessing outcomes of arts programming.

Admission of the very elderly to the intensive care unit: Family members’ perspectives on clinical decision-making from a multicenter cohort study

This article describes family members’ perspectives about care provided to very elderly critically ill patients. There is incongruity between family preferences for end-of-life care and actual care received for very elderly patients who are admitted to the intensive care unit. Deficiencies in communication and decision-making may be associated with prolonged use of life-sustaining treatments in very elderly critically ill patients, many of whom ultimately die.

A comparative descriptive study of characteristics of early- and late-onset dementia family caregivers

Characteristics of early- and late-onset dementia family caregivers were described and compared. A significantly higher proportion of caregivers of younger adults were spouses and gainfully employed compared with those of older adults; they had more years of schooling, took care of a person with more severe impairments, received more help, perceived themselves as better prepared to deal with future needs, and better informed about services. They did not differ from caregivers of older adults in terms of psychological distress, role confidence, self-efficacy, and social support. This study highlights differences and similarities to be considered in the development of services tailored to the specific needs of each group.
Recognition & Support of Carers

Brief online surveys to monitor and evaluate facilitated peer support groups for caregivers of children with special needs
This study aimed to establish whether brief, online surveys can be used for monitoring and evaluating peer support groups for caregivers of children with special needs. Two surveys were developed. Responses revealed both positive and negative aspects of group participation. Linked data on expectations and experiences provided important feedback for the program. Brief, online surveys are a suitable mechanism for ongoing monitoring and evaluation of peer support group programs for caregivers.

‘Recognized, valued and supported’? The experiences of adult siblings of people with autism plus learning disability
Our study explores the expectations of social care among adult siblings. Siblings, although reflecting on the difficulties of growing up with someone who had autism, expressed a commitment towards their brother or sister. While some siblings described positive relationships with services, many felt marginalized. Practitioners largely confirmed their perceptions, while offering a justification for why they struggled to engage with adult siblings.

Carer Health & Wellbeing

Correlates of caring for the drinkers and others among those harmed by another's drinking
This study identifies the correlates of caring for harmful drinkers and others, and examines how caring for that person impacts on respondents' well-being and use of services. The study reveals that the respondents who cared for others because of the other's drinking reported lower quality of life than the respondents who did not have to do this. The findings of the study suggest that the drinking of family and friends can be a substantial burden for their households, families, friends and others. Policy approaches that reduce the amount of heavy drinking, particularly heavy drinking in a single occasion, are likely to reduce the burden of caring for others because of other's drinking.
Resilience in families with adolescents suffering from traumatic brain injuries


This study aims to co-construct the building blocks for an intervention program to support family resilience in conjunction with families with an adolescent suffering from traumatic brain injury and rehabilitation professionals. This study offers promising avenues for practitioners and researchers in nursing and other fields with respect to the implementation of concrete strategies to support the resilience process of families facing particularly difficult times in their lives.

Which variable is the strongest adjusted predictor of quality of life in caregivers of patients with dementia?


This study measures caregivers' quality of life (QOL) and determines its predictors. Caregiver burden was proposed as the strongest adjusted predictor for caregivers' poor QOL. Therefore, it seems that interventions to reduce caregiver burden can be effective in enhancing caregivers' QOL.

The relationship between burden and well-being among caregivers of Italian people diagnosed with severe neuromotor and cognitive disorders


This study aimed to disentangle the relationship between burden and well-being. Participants perceiving high burden reported higher levels of depression related emotions, lower life satisfaction and lower resilience than participants perceiving low burden. Findings suggest that the joint assessment of burden and well-being dimensions allow for the identification of resources that can be usefully included in interventions addressed to caregivers.

Social Inclusion, Relationships & Community Participation

Do caregiving burden and satisfaction predict loneliness in older care recipients?


This study assessed the extent to which caregiving burden and satisfaction of primary family caregivers predicted loneliness among their older care recipients. Analyses showed that caregiving burden was insignificant in explaining loneliness, whereas greater caregiving satisfaction was found significant in explaining lower levels of loneliness. The results and implications for further research and practice are discussed.
The effect of a personalized dementia care intervention for caregivers from Australian minority groups


This study tested the hypothesis that personalized caregiver support provided by a team led by a care coordinator of the person with dementia would improve competence for caregivers from minority groups in managing dementia. The intervention group showed a significant increase in the caregivers’ sense of competence and mental components of quality of life.

No matter how I think, it already hurts: Self-stigmatized feelings and face concern of Chinese caregivers of people with intellectual disabilities


This study explored internalised self-stigma among family caregivers of people with intellectual disability (ID) in China. The results highlighted the role of stigmatised feelings instead of cognitive thoughts in hurting caregivers in the Chinese context. Feelings of being marginalized within the family and shame may be more face culture-related concern.

Exploratory evaluation and initial adaptation of a parent training program for Hispanic families of children with autism


This paper reviews literature on cultural processes in prevention and intervention research with Latino families. Overall, many prevention and intervention programs have either been developed specifically for Latino families or have been modified for Latino families with great attention paid to the socio-cultural needs of these families. Nevertheless, few studies have tested the role of cultural values or acculturation processes on outcomes.

Needs of Chinese families with children with developmental disabilities: A qualitative inquiry


This inquiry focused on the perceptions that Chinese families of children with developmental disabilities have pertaining to their needs. Sufficiency needs were more child focused among respondents and survival and enhancement needs for families in this study were directly linked to the whole family unit in promoting the family’s overall functioning. The dynamic nature of needs suggests that more than one need may motivate families’ desires for enhanced family quality of life.
**GLBTI Carers**

**Disparities in health and disability among older adults in same-sex cohabiting relationships**


This study compared indicators of impaired health and disability between older adults in same-sex cohabiting relationships and their peers in opposite-sex cohabiting relationships. Compared with their peers in opposite-sex relationships, older men in same-sex relationships exhibited greater odds of psychological distress, and older women in same-sex relationships experienced elevated odds of poor/fair health, needing help with activities of daily living and instrumental activities of daily living, functional limitations, and psychological distress.

**Young Carers**

**Maintaining everyday life in a family with a dying parent: Teenagers' experiences of adapting to responsibility**


This study sought to gain knowledge about the ways that teenagers themselves describe living in a family with a seriously ill and dying parent. Teenagers were greatly affected by their parent's illness and took on great responsibility for supporting their parents and siblings, and for maintaining family life. Lacking sufficient information and support left them rather unprepared, having to guess and to interpret the vague signs of failing health on their own, with feelings of uncertainty and loneliness as a consequence. Our results add further support to the literature, reinforcing the need for an approach that uses a systemic perspective and considers the family to be the appropriate unit of care and offers a suitable support system.

**Disclaimer**

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