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

Whose responsibility? Resilience in families of children with developmental disabilities

Families with children with disabilities are at higher risk of stress, financial disadvantage and breakdown. In recent decades, research and policy have shifted focus from these problems to a strengths-based approach, using concepts such as family resilience. Using interviews with parents of children with developmental disabilities based in New South Wales, this paper begins to answer the question of who is responsible for family resilience.

System-wide information about family carers of adults with intellectual/developmental disabilities - A scoping review of the literature

A scoping review was conducted to identify system-wide information needed about family carers of adults with intellectual/developmental disabilities (I/DD) that would help improve service quality. Service use and need were associated with the presence of challenging behaviours among individuals with I/DD as well as carer demographics and health status. Also, carers’ subjective view of how well they think they can provide for their child in the future was an important determining factor of service need.
Rethinking resilience in families of children with disabilities: A socioecological approach
This paper explores resilience in families of children with disabilities. We show that families who reported doing well were able to conduct their lives with a 'business as usual' approach to their daily lives, in contrast to families who were struggling and had reported that disability had overtaken their day-to-day routines and activities. We show the importance of social context in understanding family 'well-doing' in families with disability.

Inconsistencies in the roles of family- and paid- carers in monitoring health issues in people with learning disabilities: Some implications for the integration of health and social care
Changes in the living circumstances of people with learning disabilities have seen responsibility for their health become the provenance of paid- and family-carers. Findings revealed that the role of these carers was undefined, leading to difficulty in deciphering who was responsible for the health care of the people they supported. A more consistent approach to health care within the community setting is needed, especially in terms of the remit of paid- and family-carers and with the integration of health and social services.

‘It’s afforded us a huge flexibility’: The impact of ‘Disabled Children’s Access to Childcare Pilots’ on families with a disabled child in England
The Disabled Children’s Access to Childcare (DCATCH) pilots was an initiative designed to improve access to childcare for disabled children. The results of the DCATCH initiative support other research which argues that whilst cost is a significant factor around childcare choices for families with a disabled child, having confidence in the childcare provider’s ability to meet specific needs and providing positive experiences for the disabled child are also key factors.

Fathers and mothers of children with learning disabilities: Links between emotional and coping resources
This study compared emotional and coping resources of two parent groups – children with learning disabilities (LD) versus with typical development – and explored how emotional resources may explain differences in parents’ coping resources. As hypothesized, parental emotional resources contributed to coping resources, although this differed partially between groups. Discussion focuses on the unique value of emotional resources for coping resources in both populations.
Mental Health

The recovery framework as a way of understanding families' responses to mental illness: Balancing different needs and recovery journeys
This paper considers if the recovery framework is helpful in understanding families' experiences. We were able to highlight similarities and points of tension between consumer and family recovery tasks. Family response to mental illness is a dynamic, multilayered process rather than a static and enduring role of caregiving. The recovery framework offers an alternative way to understand a family's response to mental illness.

Transition-age children with mental illness: Hearing the voices of mothers
This paper explores the perspectives of mothers of transitional age (18-25) children diagnosed with mental illness. Results indicate a dynamic shift in the mothering role during this time period. Findings also suggest mothers and their transition-age children need emotional and practical support from social workers and other mental health professionals.

What do relatives experience when supporting someone in early psychosis?
This research aimed to explore relatives' experiences of supporting a relative in early psychosis. Four key themes reflecting relatives' understanding and management of psychosis were identified. This study has clear implications for improvement in how relatives are supported, such as; clearer guidance for staff about confidentiality, treating relatives as partners in care and providing better quality information for relatives.

Serious/Terminal Illness

Living in the shadow of cancer: The experience of first degree relatives of patients with advanced colorectal cancer
This study aims to gain an in depth understanding of the experiences, beliefs and needs of first-degree relatives of patients diagnosed with advanced colorectal cancer. This study highlights the profound impact of advanced colorectal cancer on the wider family, and suggests a role for palliative care in identifying and supporting their unmet needs.
Understanding the barriers to identifying carers of people with supportive and palliative care needs in primary care


This study explored the barriers to identifying carers of people at the end of life in primary care, and why carers do not self-identify. Transition into the caring role was seen as a gradual process and carers did not necessarily identify with being a ‘carer’, meaning support was often initiated in response to a crisis. Strategies to identify and support carers should be commenced early in the illness trajectory to prevent crises and need to be sensitive to the complexities of the primary care context. Primary care teams also need to work together to ensure that carers’ needs are legitimised so that they are empowered to self-identify.

Living close to a person with cancer: A review of the international literature and implications for social work practice


To help family caregivers (FCs), social workers need to understand the complexity of FC's experiences and challenges. Various experiences, symptoms and burden related to caregiving responsibilities are described and discussed. The understanding evolving from this study about the FC’s own health risk, caregiver burden and experiences over time can enhance social worker's awareness of FC's challenging situation and the potential impact this has on the FC's ability to provide care to the patient.

Family caregivers of cancer patients: Perceived burden and symptoms during the early phases of cancer treatment


This study investigated levels of symptoms, caregiver burden, and changes over time in family caregivers (FC) of cancer patients. FCs experienced high levels of depressive symptoms and sleep disturbance, low levels of fatigue, and low to moderate levels of caregiver burden, yet these symptoms remained relatively stable over time. Being female and not being employed were factors associated with an increased risk of symptoms and caregiver burden. The understanding evolving from this study can enhance social and health care professionals' awareness of FCs' challenging situation and the potential impact this has on the FCs' ability to provide care to the patient.
Aged & Dementia

Dementia Knowledge Assessment Tool Version Two: Development of a tool to inform preparation for care planning and delivery in families and care staff


Care for the person with dementia requires understanding of the person’s perspective, integrated with knowledge of dementia’s trajectory and appropriate care. Establishing a shared staff–family understanding of the dementia trajectory and care strategies is critical to embarking upon the development and implementation of collaborative long term and end-of-life care plans. This tool can help establish education programs and informational resources in a way that facilitates comparisons across family and staff carer groups.

What is known about dementia care recipient violence and aggression against caregivers?


This article examines the issue of aggression towards dementia carers with a focus on what is known and where further research is needed. Rates of severe aggression by dementia care recipients against caregivers are estimated at greater than 20%, and may be the strongest predictor of nursing home placement. Measures containing both assessment of behaviour and objective measures of caregiver trauma are needed, along with interventions aimed at educating and protecting caregivers while respecting communicative properties of behaviour.

Electronic tracking for people with dementia: An exploratory study of the ethical issues experienced by carers in making decisions about usage


Electronic tracking through GPS is being used to monitor and locate people with dementia who are vulnerable to becoming lost. This article examined ethical issues associated with use in a domestic setting. The study explored the values, beliefs and contextual factors that motivated carers to use electronic tracking. It examined the extent of involvement of the person with dementia in decision-making and explored the various ethical dilemmas encountered by carers when introducing the tracking system. As an issue that emerged from the interviews, specific attention was paid to exploring covert usage.
The transition to parent care: Costs, commitments, and caregiver selection among children
This research traced the process of caregiver selection among adult children. The indicators for caregiving commitments showed the importance of reciprocity, path dependency, and parental expectations as motivational forces affecting the process of caregiver selection. Gender effects revealed the primacy of the mother–daughter tie, as daughters were overrepresented only in transitions to mother care.

The effects of declining functional abilities in dementia patients and increases in psychological distress on caregiver burden over a one-year period
The degree to which changes in caregiver burden over a one year period can be predicted by dementia patients’ functioning and caregiver psychological stress was examined. Patient functioning predicted overall changes in caregiver burden, but caregivers’ psychological symptoms were the best predictors for specific types of caregiver burden. Interventions should target reduction of psychological symptoms in order to reduce caregiver burden.

Quality end-of-life care for dementia: What have family carers told us so far? A narrative synthesis
We explored what quality end-of-life care for dementia is from the perspective of family carers. There was an overarching theme of ‘A family’s belief of death and their choice of treatment’. It is difficult to define what constitutes high-quality end-of-life care for people with dementia from the perspective of family carers. Their views expressed in the literature appear to demonstrate more variation of preference of care and their uncertainty of this.

Recognition & Support of Carers

Enhancing preparedness and satisfaction of caregivers of patients discharged from an inpatient rehabilitation facility using an interactive website
The aim of this project was to test the use of web-based resources to enhance the preparedness and satisfaction of caregivers following a patient’s discharge from inpatient rehabilitation. This preliminary study supports the clinical relevance of internet resources to improve caregiver preparation. With shortened hospital stays, providing online services for caregivers can complement other healthcare services.
Social support sources, types, and generativity: A focus group study of cancer survivors and their caregivers


In this study, focus groups explored the types of support that people with cancer and their caregivers experienced and valued. Results showed that although men and women with cancer and caregivers identify similar sources of support, they experience different types of support. Results also indicated a desire among participants to help and support others – a concept referred to as generativity.

A systematic review of Internet-based supportive interventions for caregivers of patients with dementia


This study aims to provide an overview of the effectiveness, feasibility, and quality of internet interventions for informal caregivers of people with dementia. The overall level of evidence was low. However, the results demonstrate that internet interventions for informal dementia caregivers can improve various aspects of caregiver well-being.

Carer Health & Wellbeing

Feeling that life is not worth living (death thoughts) among middle-aged, Australian women providing unpaid care


This paper aims to identify the proportion of female carers who experience death thoughts and the factors associated with these thoughts. 7.1% of female carers had felt life was not worth living in the previous week and were classified as having experienced death thoughts, compared with 5.7% of non-carers. Carers with death thoughts had poorer physical and mental health, higher levels of anxiety, lower levels of optimism, and reported less social support. These findings add to the growing body of evidence on suicide-related thoughts and behaviours in carers and have implications for health professionals and service providers.
Correlates of psychological distress in study partners of older people with and without mild cognitive impairment (MCI) – The Sydney Memory and Ageing Study


We aimed to establish correlates of psychological distress in study partners of individuals with and without nonclinical mild cognitive impairment (MCI). Objective impairment measures were not associated with distress in partners or supporters. However, study partners’ appraisals of functional and behavioural symptoms were linked to increased distress even in this very mildly affected community cohort.

Clarity through the kaleidoscope: Gaining consensus on the main causes of carer burden from professional and carer perspectives


This study developed and piloted a Carers' Alert Thermometer to alert healthcare workers to increasing carer burden and provide guidance on appropriate interventions. Understanding the current caring situation and supporting carer’s health and well-being were the main priorities. Despite the complex needs of carers, consensus on the main burdens exists which can be utilised in an alert tool to identify burden and guide targeting of support and resources.

Caregiver burden: The strongest predictor of self-rated health in caregivers of patients with dementia


The aims of our study were to measure caregivers’ health as well as identify its adjusted relevant predictors. Caregiver burden was not only significantly associated with poor self-rated health but it was also recognised as the strongest predictor of caregivers’ self-rated health. Therefore, it seems that development of intervention programs to reduce caregiver burden can be considered as important step in promoting caregivers’ health.

Caregiver burden: A clinical review


This review outlines the epidemiology of caregiver burden; provides strategies to diagnose, assess, and intervene in clinical practice; and evaluates evidence on interventions intended to avert caregiver burden and distress. Physicians have a responsibility to recognize caregiver burden. Caregiver assessment and intervention should be tailored to the individual circumstances and contexts in which caregiver burden occurs.
Social Inclusion, Relationships & Community Participation

A narrative enquiry of experienced family carers of people with dementia volunteering in a carer supporter programme


The present study explored the impact of participating in a carer supporter programme in the context of previous caring experiences. The results indicated that most carer supporters naturally reflected on the positive impact of having shared experiences with the newer carers. The findings of the study indicate that the carer supporter role has potential to facilitate new roles, activities and social identities, but participation needs to be considered in relation to potentially stressful transitional points throughout the caring career.

Spouse and child availability for newly disabled older adults: Socioeconomic differences and potential role of residential proximity


This paper examines the role of child and spousal availability in facilitating community-based care for disabled older adults. Lower socioeconomic status (SES) was associated with less availability of a spouse but greater availability of children. Older adults who had at least one child living near them were less likely to go to a nursing home and less likely to depend on formal care. Understanding SES variations in the informal care resources, and potential role of child geographic availability, may inform the development of cost-effective community-based care programs and policies.

CALD Carers

“The persistence of parent repayment” and the anticipation of filial obligations of care in two Thai provinces


This paper explores the expectations that individuals have from their children when they become very old. The expectations varied substantially by the number of children and income, with those with higher income reporting lower expectation. Those living in a poorer province had greater expectations from their children in old age. This suggests that, for those with less financial resources, children remain the main care provider for the elderly.
Individually-tailored support for ethnically-diverse caregivers: Enhancing our understanding of what’s needed and what works


We discuss a program serving ethnically-diverse caregivers in New York. Participants reported significantly reduced stress and burden. Respite was the most requested service, belying an assumption underlying policies and services that families, particularly among minority populations, can and will care for their older members. Thus, services must be carefully tailored to meet actual caregiver needs, including provision of alternatives that reduce caregiver involvement.

Rural Carers

The benefits of e-health support for older family caregivers in rural areas


We conducted a study comparing rural family caregivers receiving e-health caregiver support with a control group receiving conventional, non-e-health, caregiver support. After 18 months, the benefits of support were evaluated. In all domains the e-health group scored significantly higher than the control group. All caregivers in the control group found conventional support to be beneficial, but also stressed unmet needs related to the conventional support being standardised and non-flexible. The study suggests that providers of caregiver support should offer e-health support as an alternative to conventional caregiver support, as it can be more beneficial to family caregivers.

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