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

Parents’ perspectives on inclusive schools for children with autism spectrum conditions


This study reviewed studies of children with autism spectrum conditions (ASC) for parents' perceptions of aspects they believed contributed to inclusive mainstream school settings. The school was considered important in creating an environment that enabled inclusion. At the societal level, funding and legislative policies were considered important. By understanding these aspects parents' inclusion concerns may be better addressed and strategies developed to improve inclusion in mainstream schools.

The marital experiences of couples who include a child with autism


We investigated married couples’ perceptions of marital quality and explored factors that contributed to marital longevity. The data indicated, in general, that having a child with autism has broad effects on relationship experiences, including some partners feeling more bonded over the care of their child. We discuss implications for clinicians, limitations, and potential future directions for additional research.
The impact of four family support programmes for people with a disability in Ireland


This article reports on an evaluation of four family support programmes for families of people with a disability. Findings suggest that participation in the programmes enhanced knowledge, attitudes, and competencies of families and also impacted their ability to advocate for their family member and to connect with the community. Whilst outcomes were positive, further follow-up would be required to ascertain if sustained capacity building took place.

Financial and employment impact of intellectual disability on families of children with autism


This study describes additional impact on families of children with intellectual disability (ID) in addition to autism spectrum disorder (ASD). Compared with ASD alone, caregivers of children with both ASD/ID were more likely to report financial difficulty, cutting work hours, and stop working. We conclude that having ID in addition to ASD may be associated with greater negative impact on family financial and employment burden. Recognition of ID in addition to ASD is important to tailor the clinical approach and sufficiently support families.

Mental Health

Depression and service use among caregivers dually involved in the child welfare and mental health systems


This study investigated the prevalence of depression, use of mental health services, and correlates of service use among caregivers who are dually involved in the child welfare and child mental health systems. Depression rates exceeded those found among caregiver involved in either the child welfare or child mental health systems. Rates of service use were higher than found in existing research. As expected, racial differences and depression were associated with service use; contrary to expectations, full time employment was not associated with service use. Discrepancies between this study and existing research are discussed, as are practice, policy, and research implications.
Stigma by association among family members of people with a mental illness: A qualitative analysis


We investigated experiences of stigma by association among family members of people with mental illness. Participants reported experiencing stigma by association from community members, mental health professionals, and civil servants. Familial relationship, co-residence, and gender appeared to play a role in stigma experiences. These factors point to the need for tailored education and support provision to family members of people with mental illness.

Children’s mental health providers’ perceptions of mental health literacy among parents and caregivers


This article describes the perceptions of child and family mental health providers' perceptions regarding the amount, accuracy, and origin of mental health literacy in the parents of the children they treat. Providers perceived parent mental health literacy as low, inaccurate, and inconsistent. In addition, providers indicated that parents rely on informal sources of support, such as friends and family for information about children's mental health. Implications for social work researchers, practitioners, and the children and families they serve are discussed.

The role of relatives in pathways to care of patients with a first episode of psychosis


This study explored the role of relatives in pathways to care of patients with a recent onset of psychosis. Among health professionals, general practitioners were those most frequently contacted, followed by psychiatrists, neurologists or psychologists. Stigma and wrong attribution of psychotic symptoms were the main reasons for help-seeking delays.

Mental health professionals’ views of the parents of patients with psychotic disorders: A participant observation study


This study explored professionals’ views of parents of patients with psychotic disorders. Some parents were described as a helpful resource, but others were thought to hinder treatment. Conflicts between staff members and parents were commonly due to their differing views on the treatment of the patient. Professionals should recognise families with adverse experiences and help parents fulfil their potential to become resources for their children with psychosis.
Serious/Terminal Illness

Exploring identity in the ‘figured worlds’ of cancer care-giving and marriage in Australia

This paper examines spouses’ reflections on the term ‘carer’. Findings depict identification with the ‘spouse’ and ‘carer’ label as relationally situated and dependent on meaningful interaction. Of most significance to practitioners and policy makers, the title provides carers with an opportunity to position themselves as entitled to inclusion and support, and providing health professionals with a potential indicator of a spouse’s increased burden.

Development of a conceptual model of cancer caregiver health literacy

The study aimed to develop a conceptual model to describe the elements of cancer caregiver health literacy. Major themes included: access to information, understanding of information, relationship with healthcare providers, relationship with the care recipient, managing challenges of caregiving and support systems. The study extends conceptualisations of health literacy by identifying factors specific to caregiving within the cancer context.

Dyadic coping and relationship functioning in couples coping with cancer: A systematic review

We assessed the relationship between dyadic coping and relationship functioning in couples coping with cancer and whether intervention studies aimed at improving dyadic coping were able to enhance the relationship functioning of these couples. This review showed that adequate dyadic coping may improve relationship functioning, while dysfunctional dyadic coping may impede relationship functioning. More insight on how to expand the dyadic coping of these couples might facilitate improvements in the quality of cancer care.

Palliative care caregivers’ grief mediators: A prospective study

The aim of the study is to identify the mediators of complicated grief in caregivers. The results show relational factors are relevant, but we must consider the reciprocal influence among factors, as well as their impact on specific symptoms.
Mothers and fathers coping with their children’s cancer: Individual and interpersonal processes


This study examined individual and interpersonal processes of coping and emotional distress in a sample of mothers and fathers of children with recently diagnosed cancer. Interpersonal analyses of coping and distress indicated that mothers’ and fathers’ coping as well as depressive symptoms were significantly correlated. Implications for interventions to enhance effective coping for parents of children with cancer are highlighted.

Aged & Dementia

Moderating effect of self-efficacy on the relation between behavior problems in persons with dementia and the distress they cause in caregivers


This study analysed the moderating effect of self-efficacy for managing behavioural and psychological symptoms in dementia (BPSD) on the distress these problems generate in family caregivers. Caregivers having to deal with a high frequency of behaviour problems but with high levels of self-efficacy presented significantly lower levels of distress compared to those caregivers with low levels of self-efficacy.

Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: Systematic review and meta-analysis of randomised controlled trials


This study aims to assess whether educational programmes for caregivers of individuals with dementia living in the community are effective on caregiver burden, quality of life (QoL), depression and transitions to long stay care compared with usual care. Educational programmes have a moderate effect on caregiver burden and a small effect on depression. Evidence of an effect on QoL and transitions to long stay care remains unclear.
Evaluation of a problem-solving (PS) techniques-based intervention for informal carers of patients with dementia receiving in-home care


This study evaluated the effectiveness of problem-solving techniques-based intervention in enhancing carers’ physical and emotional capacity to care for relatives with dementia living in the community. Problem solving techniques improved carers’ caregiving competence, coping, burden, and perceived stress. This may reduce dependence on primary, psychiatric, and institutional care.

Voices of Alzheimer caregivers on positive aspects of caregiving


This study aimed to discover positive gains as constructed by family caregivers of relatives with Alzheimer’s disease. Ten themes related to positive gains were identified: (a) insights about dementia and acceptance of the condition, (b) a sense of purpose and commitment to the caregiving role, (c) feelings of gratification when the care-recipient (CR) was functioning relatively well, (d) mastering skills to handle the CR, (e) increased patience and tolerance, (f) cultivating positive meanings and humour amidst difficult circumstances, (g) letting go of things, such as when the CR’s qualities had been lost or personal agenda had become unrealistic, (h) developing a closer relationship with the CR, (i) finding support, and (j) feeling useful helping other caregivers.

Recognition & Support of Carers

Maintaining the potential of a psycho-educational program: Efficacy of a booster session after an intervention offered family caregivers at disclosure of a relative's dementia diagnosis


This study sought to test the efficacy of the booster session in maintaining or recovering program effects at six months post-program. Analyses revealed one significant positive effect of the booster session: emergence of preparedness to provide care. Moreover, with or without the booster session, the program continued to have a positive effect on psychological distress and contributed to the emergence of self-efficacy in dealing with caregiving situations.
The “not yet” horizon: Understandings of the future amongst couples living with dementia

This study aims to explore how the future is understood by couples living with dementia. The findings show that persons with dementia describe the here and now in ways that take the gloomy future they dread as a point of reference, and as a result of this, they operate in what we term “the not yet horizon”. But while they take for granted that there is a horizon that they have not yet reached, their spouses always seem to focus on the horizons that they have already crossed.

The positive aspects of caregiving in dementia: A critical review of the qualitative literature

The aim of this review was to critically evaluate the empirical findings of qualitative studies that have explored positive aspects of caregiving in dementia. Carers described multiple positive dimensions of caregiving and identified several factors that were important in supporting their positive caregiving experience. The present review evidences a solid base of understanding of the positive aspects of caregiving in dementia from which concepts and theories can be further developed.

What is left unsaid: An interpretive description of the information needs of parents of children with asthma

This study gained insight into the information needs and deficits of parents of children with asthma. Participants’ knowledge did not always reflect time since diagnosis, and information needs and deficits persisted for years. An asthma management information hierarchy was identified, starting with the most foundational, recognising severity; followed by acute management; prevention versus crisis orientation; and knowing “about” asthma. These parents’ pervasive unmet information needs and deficits highlight the need for comprehensive, problem-oriented asthma education.

A systematic review of telehealth tools and interventions to support family caregivers

We conducted a systematic review of studies employing telehealth interventions which focused on family caregivers’ outcomes. More than 95% of the studies reported significant improvements in the caregivers’ outcomes and that caregivers were satisfied and comfortable with telehealth.
Carer Health & Wellbeing

Developing organizational guidelines for the prevention and management of suicide in clients and carers receiving palliative care in Australia


This article describes the process of developing a suicide guideline in palliative care. The final guideline incorporated specific action plans for each discipline; mandatory training for all staff was endorsed through a recognised suicide alertness training program; advanced training in suicide intervention skills for key clinical staff will be required; and a “Rapid Plan Team” was recommended.

Psychological distress and loneliness in caregiver of advanced oncological inpatients


The objective of this study is to examine the relationships between levels of loneliness, anxiety, depression, and other variables on primary caregivers and cancer inpatients. Loneliness and anxiety scores were significantly higher for the primary caregivers of inpatients with terminal stage of cancer than primary caregivers of inpatients with advanced stage of cancer. Excluding the cancer stage, loneliness and anxiety were primarily associated with the socio-demographic factors of primary caregivers rather than the characteristics of patients.

Social Inclusion, Relationships & Community Participation

Interrelations between siblings and parents in families living with children with cancer


This study investigated the relationships between parental family functioning and siblings’ health-related quality of life (HRQOL) and described interrelations between the experiences of parents and siblings of children with childhood cancer. We found strong correlation between parental family functioning and siblings’ HRQOL. The results suggest the importance of family nursing interventions directed to individual family members and the family unit that focus on strengthening the parent–sibling relationship and supporting families who are experiencing childhood cancer.
Peer support for parents of disabled children part 2: How organizational and process factors influenced shared experience in a one-to-one service, a qualitative study


Parents of disabled children often seek support from their peers. Understanding how a sense of shared experience is fostered can help to design services that seek to provide peer support. We carried out a study involving interviews and focus groups. Organisational factors as well as characteristics of the parents offering and receiving support contribute to the sense of shared experience in one-to-one peer support. These influence whether peer support is effective and should be explicitly considered when designing and evaluating services.

To work or to care? Working women's decision-making


This study addressed the question of how working women who give care to their older parents argue for and against their decisions of working and caring and the meaning of work and care in these decisions. A majority of the interviewees emphasised the importance of work and refuted the idea of leaving work for care. On the other hand, a few interviewees brought forward their willingness to leave work which was justified by constructing care as meaningful and valuable activity as opposed to meaningless paid employment.

Person Centred Approaches / NDIS

Housing for people with intellectual disabilities and the National Disability Insurance Scheme reforms


By providing individualised funding for supports, the National Disability Insurance Scheme (NDIS) will unlock new housing options for its participants, potentially enabling the rehousing of tens of thousands of people with intellectual disabilities. However, access to affordable, secure, and appropriately designed housing in the community remains a key barrier. This article discusses the housing needs of people with intellectual disabilities; offers an overview of current housing and living arrangements, and the historical processes that have shaped them; and considers the nature and scale of housing transitions expected to occur as the NDIS rolls out into a fully operational national scheme.
CALD Carers

An examination of clinicians’ experiences of collaborative culturally competent service delivery to immigrant families raising a child with a physical disability


This study examined the experiences of clinicians working with immigrant families raising a child with a physical disability. Findings show that clinicians remove or create barriers for immigrant families in different ways, which affect their ability to provide culturally competent care for immigrant families raising a child with a physical disability. There is a lack of formal processes in place to develop collaborative treatment plans and approaches that would benefit immigrant families.

Family caregiver's perception of Alzheimer's disease and caregiving in Chinese culture


This study examined the perception of Alzheimer’s disease (AD) and caregiving among family caregivers of individuals with mild cognitive impairment (MCI) and AD in China. The findings showed that all family caregivers thought the Chinese terminology of AD brought discrimination to individuals with cognitive impairment. Traditional beliefs of respecting elders and caring for extended family members were held among family caregivers of individuals with cognitive impairment. Traditional culture provided positive influences on caring for elders with cognitive impairment. An alternative term for MCI may contribute to further reducing the discrimination brought by the old Chinese terminology of AD.

GLBTI Carers

Experiences of sexual and gender minorities caring for adults with non-AIDS-related chronic illnesses


This article features a review of the evidence regarding the experiences of sexual and gender minorities (SGMs) involved in the informal care of chronically ill friends or family members. The review found that the SGM caregiving experience is characterised by experienced and anticipated sexual and gender prejudice within health and social services systems, involvement of families of choice, and the invisibility of the needs of SGM caregivers as a community and as individuals.
Male Carers

‘Deferred or chickened out?’ Decision making among male carers of people with dementia


In this paper, we present new insight into the ways in which carers of people with dementia make decisions in the context of seemingly declining autonomy and freedom associated with the condition. We found that short-term or ‘day-to-day’ decisions were made with input from those cared for, while longer term decisions were deferred until a point when necessity meant carers had to make decisions themselves. Importantly, carers were aware of the implications of how they were making decision, including the potential impact in terms of denial of autonomy of those they care for.

Young Carers

Young adult carers: A literature review informing the re-conceptualisation of young adult caregiving in Australia


The aim of this article is to provide a foundation for the re-conceptualisation of young adult carers (YACs) as a distinct carer cohort who, without suitable recognition and specifically targeted support, may experience significantly reduced future life opportunities. The review explores the complex nature of young adult caregiving in Australia. Explanations as to why young adults are increasingly undertaking these informal caregiving roles and how YACs differentiate from their non-carer peers follows.

One million and counting: The hidden army of young carers in Canada


In Canada, research and awareness for young carers remains in its infancy and available national datasets have yet to be examined in relation to youths providing unpaid caregiving. As a result, this research provides the first trend analysis of youth-based caregiving in Canada. Methodological limitations of official statistics are also discussed in terms of conceptual and operational constraints limiting the full identification of all those potential young carers.

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