

RESEARCH SNAPSHOT

FEBRUARY 2018

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



A pilot study of social inclusion and quality of life for parents of children with autism spectrum disorder

Due, C., et al. (2018). Journal of Intellectual & Developmental Disability 43(1): 73-82.

This study investigated quality of life (QoL), social inclusion and perceptions of parents, of specialist centres offering both childcare and early intervention for pre-school children. Parents had typically low levels of QoL but reported a range of benefits from receiving services, including increased levels of community participation and increased competence and confidence in themselves as parents.

Examining the utilisation and usefulness of social support for mothers with young children with autism spectrum disorder

McIntyre, L. L. and M. Brown (2018). Journal of Intellectual & Developmental Disability 43(1): 93-101.

This study examined the utilisation and usefulness of social support in American families with children with autism spectrum disorder (ASD). Mothers of children with ASD reported using a combination of formal and informal supports. These were perceived to be helpful. Sociodemographic variables, child behaviour problems, satisfaction with the diagnostic process, and access to information predicted social support utilisation. Social support utilisation varies as a function of different child, family, and service variables.

Mental Health

Brief Psycho-Education for Caregivers of Persons With First Episode Psychosis

Kapse, P. P. and M. Kiran (2018).

Caring for the persons with first episode psychosis is challenging and demanding. Numerous studies have shown that high burden and negative expressed emotions among caregivers can lead to early relapse in patients with first episode psychosis. This study aimed to evaluate the effects of brief psychoeducation on caregivers' burden and expressed emotions. Results demonstrate the importance of psychoeducation intervention in reducing the burden and negative expressed emotions.

Caregiver burden and illness perceptions in caregivers of medically hospitalized youth with anorexia nervosa

Matthews, A., et al. (2018). Eating Behaviors 29: 14-18.

This study examined caregiver illness perceptions about anorexia nervosa (AN), symptom severity indicators, and caregiver burden in a sample of medically hospitalized youth with AN. Findings indicated that caregiver beliefs about negative consequences of AN were associated with caregiver burden, independent of youth age, sex, illness duration, and diagnosis. Findings suggest that the subjective experience of having a youth with AN, is a greater determinant of caregiver burden than objective indicators of illness severity.

The last taboo: The experience of violence in first-episode psychosis caregiving relationships

Onwumere, J., et al. Psychology and Psychotherapy: Theory, Research and Practice

This study explored the subjective accounts of informal carers supporting a relative experiencing their first episode of psychosis who has also behaved violently towards them. Analyses identified seven key themes. Reports by informal carers about experiencing violence and victimization from their relatives with psychosis are an important issue in some caregiving relationships during the first episode. Developing a more informed understanding of the specific needs of these carers and the caregiving relationship is indicated.

Relation Among Anxiety and Family Burden in Primary First-Degree Caregivers of Outpatients with Mental Disorders in Turkey

Dikeç, G., et al. (2018). Issues in Mental Health Nursing 39(2): 142-150.

This study determined the relation among anxiety and family burden in primary first-degree relative caregivers of outpatients with mental disorders in Turkey. Results indicated primary caregivers of patients with mental disorders had a moderate level anxiety, and as anxiety increased, family burden also increased. Results suggest that mental health nurses should plan interventions not only for patients, but also for their caregivers.

A survey of caregiver burden in those providing informal care for patients with schizophrenia or bipolar disorder with agitation: results from a European study

Blanthorn-Hazell, S., et al. (2018). Annals of General Psychiatry 17(1): 8.

Agitation is a common feature of bipolar disorder and schizophrenia. Previous research indicates that specific symptoms impact caregiver burden in these conditions, but the impact of agitation on caregiver experience is poorly understood. The aim of this study was to characterise caregiver burden in providers of informal care for patients with bipolar disorder and schizophrenia who experience agitation.

Drug / Alcohol Dependency

Mothers' Experiences of Supporting Adolescent Children Through Long-Term Treatment for Substance Use Disorder

Smith, J. M., et al. (2018). Qualitative Health Research 28(4): 511-522.

In this study, we explored the experiences of four mothers parenting children through long-term substance abuse treatment. The mothers' experiences were explored within a three-dimensional narrative inquiry space of temporal, social, and situated experience. Four narrative accounts were co-composed. Four narrative threads were also theorized: navigating complexities; loud silences; places, spaces, and the in-between; and living within one another's stories. These threads are discussed in relation to health and social care practices.

Serious Illness / Chronic Condition

eHealth interventions for family carers of people with long term illness: A promising approach?

Sin, J., et al. Clinical Psychology Review.

This paper reports on the effectiveness of eHealth interventions for carers' wellbeing in family carers of people who have a long term illness. Interventions commonly aimed to promote carers' knowledge, self-efficacy, caregiving appraisal, and reduce global health morbidities. Overall, carers appreciate the flexibility and self-paced nature of eHealth interventions, with high rates of satisfaction and acceptability.

Informal caregivers' experiences of caring for people receiving dialysis: A mixed-methods systematic review

Hoang, V. L., et al. Journal of Renal Care

This study reviewed studies about the perspectives and experiences of caregivers for adults receiving either haemodialysis or peritoneal dialysis. This review substantiates that caregiver burden is due to the unrelenting nature of complex dialysis-specific activities although resilience often develops.

Needs of informal caregivers across the caregiving course in amyotrophic lateral sclerosis: a qualitative analysis

Galvin, M., et al. (2018). BMJ Open 8(1).

The objective of this analysis is to explore the needs of informal amyotrophic lateral sclerosis (ALS) caregivers across the caregiving course. This study has shown the consistency and adaptation in what caregivers identified as helpful in their role, across 12–18 months of a caregiving journey. Support needs are clearly defined, and change with time and the course of caregiving. Caregivers need support from family, friends and healthcare professionals in managing their tasks and the emotional demands of caregiving.

Palliative Care / Bereavement

Family carers' experiences of coping with the deaths of adults in home settings: A narrative analysis of carers' relevant background worries

Thomas, C., et al. Palliative Medicine 0(0)

This study illustrates the relevance of 'relevant background worries' in family carers' accounts of caring at home for a dying adult. Two themes are discussed: whether relevant background worries are important enough to be identified and responded to and; how such worries could be picked up and managed by professionals. It is argued that the quality of clinical practice could be improved if specialist palliative care teams identified and responded to support needs associated with family carers' relevant background worries.

The incompatibility of healthcare services and end-of-life needs in advanced liver disease: A qualitative interview study of patients and bereaved carers

Hudson, B., et al. Palliative Medicine 0(0)

This study explored the needs of patients and carers with liver disease towards the end of life, evaluated how existing services meet need, and examined patient and carer attitudes towards palliative care. The needs of patients with liver disease and their carers are frequently incompatible with the healthcare services available to them towards the end of life. Novel strategies, which recognise the life-limiting nature of liver disease explicitly and improve coordination with community services, are required if end-of-life care is to improve.

Dementia

Caregiver active participation in psychoeducational intervention improved caregiving skills and competency

Tang, S.-H., et al. Geriatrics & Gerontology International

This study aims to determine whether giving dementia caregivers active psychoeducational intervention is more efficacious than passive intervention for improving their caregiving skills and reducing their caregiving burden. Active rather than passive psychoeducation, even in a short (3 months) intervention of six visits, was more efficacious for improving caregiving competence. Future studies will require larger samples.

Caregivers' interactions with health care services – Mediator of stress or added strain? Experiences and perceptions of informal caregivers of people with dementia – A qualitative study

Laparidou, D., et al. Dementia 0(0)

This study explored the experiences and perceptions of informal caregivers of people with dementia when interacting with the health care system, and whether the support received acted as a mediator of caregiver stress. Fragmentation of dementia care services, lack of training for healthcare professionals and the dearth of information for caregivers means health care services are only partially fulfilling a support role. In turn, lack of support may be intensifying caregiver stress leading to worsening in their health and well-being.

The Impact of Respite Programming on Caregiver Resilience in Dementia Care: A Qualitative Examination of Family Caregiver Perspectives

Roberts, E. and K. M. Struckmeyer (2018). INQUIRY: The Journal of Health Care Organization, Provision, and Financing 55

Through qualitative analysis from face-to-face interviews with 33 family caregivers of individuals with dementia, several themes emerged describing the path to caregiver resilience which include family dynamics, isolation, financial struggles, seeking respite, and acceptance. While much research focuses on a caregiving burden perspective, the innovation of the present study is applying the resilience framework to outcomes from respite programming.

Medical Care Tasks among Spousal Dementia Caregivers: Links to Care-Related Sleep Disturbances

Polenick, C. A., et al. The American Journal of Geriatric Psychiatry.

This study evaluated the association between dementia caregivers' medical/nursing tasks and care-related sleep disturbances. Spousal caregivers of persons living with dementia who perform medical/nursing tasks may be at heightened risk for sleep disturbances and associated adverse health consequences. Interventions to promote the well-being of both care partners may benefit from directly addressing caregivers' needs and concerns about their provision of medical/nursing care.

Usefulness of carer-held records to support informal caregivers of patients with dementia who live at home

Sato, S., et al. Psychogeriatrics

In this study, we evaluated the usefulness of the carers-held records (CHR) for patients with dementia at the municipal level. CHR were useful for informal caregivers of patients with dementia. However, care managers need to teach informal caregivers how to properly use CHR.

Feasibility of applying the psychosocial intervention STRategies for Relatives to family caregivers of patients with dementia: a case report

Kashimura, M., et al. Psychogeriatrics

The purpose of this study was to investigate the feasibility of applying STRategies for Relatives (START), a psychosocial intervention programme developed in the UK to improve caregivers' moods and quality of life, to Japanese family caregivers. Our investigation found that the Japanese version of START is a feasible option for alleviating the mental and physical burden on family caregivers of patients with dementia. This result indicates support for the service, as it can decrease care burden and improve caregivers' daily lives.

Aged

Fall concern about older persons shifts to carers as changing health policy focuses on family, home-based care

Ang, S. G. M., et al. (2018). Singapore Med J 59(1): 9-11.

Home carers are increasingly becoming essential partners in fall prevention and care delivery for older persons living at home and in the community. Family carers experience similar concerns as older persons with regard to fall risk. Identifying and addressing these concerns can potentially lower fall risk and improve fall prevention for older persons. It is timely that we incorporate the influence of Asian cultural values and unique family dynamics of outsourcing family caregiving, in the management of older persons' fall risk.

Family caregiver mistreatment of the elderly: prevalence of risk and associated factors

Orfila, F., et al. (2018). BMC Public Health 18(1): 167.

The detection of elder mistreatment is emerging as a public health priority; however, abusive behaviors exercised by caregivers are little known and rarely detected among primary health care professionals.

The impact of personal budgets on unpaid carers of older people

Woolham, J., et al. (2018). Journal of Social Work 18(2): 119-141.

This paper focuses on the impact of a personal budget on the role of unpaid carers of older budget holders. The findings offer a detailed exploration of the impact of personal budgets on carers, suggesting that even in countries with relatively well-developed systems of support for carers such as England their impact remains overlooked. The paper may be of interest to practitioners in countries that have, or are about to introduce, personal budgets or other forms of cash-for-care scheme.

Stroke / Brain Injury

Nursing home care educational intervention for family caregivers of older adults post stroke (SHARE): study protocol for a randomised trial

Day, C. B., et al. (2018). Trials 19(1): 96.

Family caregivers of aged stroke survivors face challenges such as the lack of support and the knowledge and skills to practice home care. These aspects negatively influence caregivers' burden and quality of life, the use of health services, and hospital readmissions. The aim of this research is to describe an educational intervention focused on family caregivers of stroke survivors for the development of home care.

The unmet needs of informal carers of stroke survivors: a protocol for a systematic review of quantitative and qualitative studies

Denham, A. M. J., et al. (2018). BMJ Open 8(1).

This review aimed to report and synthesise the research describing the unmet needs of carers of stroke survivors. Knowledge about the unmet needs of carers will inform the development and refinement of interventions and services to address these needs and better support carers of stroke survivors. The findings of this systematic review will be disseminated publicly and in peer-reviewed journals and may be the topic of research presentations.

Recognition & Support of Carers

How the Law Could Promote Caring Relationships which are Pivotal to the Well-being of Society

Tang, K. Leicester Student Law Review, Autumn 2017

This article focuses on the need for Parliament to acknowledge and understand the need for caring relationships in our society and how legislation needs to be used as a tool to promote them. Click [here](#) for the full article.

Predicting Caregiver Strain to Improve Supports for the Caregivers of Children With Emotional and Behavioral Disorders

Wang, T. and J. A. Anderson (2018). Journal of Family Issues 39(4): 896-916.

This study examines several predictors of caregiver strain hypothesized to be related to caring for children with emotional and behavioral disorders. Analyses demonstrated that children's externalizing symptoms are the strongest predictor for both objective strain and subjective strain. Moreover, caregivers who had experienced mental health issues reported higher levels of subjective externalized strain; biological parents tend to experience higher subjective internalized strain than other relative caregivers do.

Carer Wellbeing

Clinical utility and psychometric properties of the Brief: Coping With Problems Experienced with caregivers

DeDios-Stern, S., et al. (2017). Rehabilitation Psychology 62(4): 609-610.

The Brief Coping with Problems Experienced (COPE) is designed to assess the varying coping strategies used by individuals in response to stress. It comprises 14 scales, each of which assesses the degree to which a respondent utilizes a specific coping strategy. This brief summary provides a review of the psychometric properties of the Brief COPE with caregivers.

The StressLess Mobile App Study: Helping Carers Thrive

The StressLess app features a self-paced program on stress management, as well as prompts and individual feedback to help carers monitor their stress levels and mood over time. The results showed one in four carers experienced a decline in stress symptoms, compared with 15 per cent in the control group and demonstrated the potential for the StressLess app to deliver more accessible and cost-effective stress management and coping strategies to carers. Click [here](#) for the full report.

Social Inclusion, Relationships & Community Participation

Advancing Care for Family Caregivers of persons with dementia through caregiver and community partnerships

White, C. L., et al. (2018). Research Involvement and Engagement 4(1): 1.

The Caring for the Caregiver program, developed at UT Health San Antonio, School of Nursing, was developed to improve support services and health outcomes for family caregivers. This paper aims to describe the engagement process undertaken to assess caregiver and community needs and how findings are informing program development.

Exploration of the perceived impact of carer involvement in mental health nurse education: Values, attitudes and making a difference

McIntosh, G. L. Nurse Education in Practice 29: 172-178.

The study sets out to explore the perceptions family carers have relating to their involvement in nurse education. Conclusions relate to the value of involvement and how connecting with students thought out their programme of study builds rapport and meaningful, authentic partnerships. However, the strategic planning and continued investment in co-production as well as a deeper understanding of the complex relationship students and carers have is needed.

LGBTIQ Carers

Older lesbians receiving home care: formal and informal dimensions of caregiving

Butler, S. S. (2018). Journal of Women & Aging 30(2): 91-110.

This study examines the caregiving experiences of lesbians, 65 and older, who utilized home care services due to acute illness or chronic disabilities. Half of those not partnered reported some level of isolation from support networks. Nearly all study participants eventually found home care workers with whom they were satisfied and even quite connected. Practice implications are discussed in context of study participants' views of how being lesbian affects their aging process and day-to-day lives.

Carers & Gender

Older male carers and the positive aspects of care

Ribeiro, O. and C. Paúl (2008). Ageing & Society 28(2): 165-183.

This study analyses the positive statements in the personal descriptions of the care-giving experience of elderly men who were caring for chronically-ill wives. The findings show that positive returns from the caring experience and role were strongly associated with previous good marital relationships and the husband's good self-rated health, and manifested in both specific coping strategies and global and situational meaning-making processes.

Recognising the “forgotten man”: Fathers’ experiences in caring for a young child with autism spectrum disorder

Paynter, J., et al. (2018). Journal of Intellectual & Developmental Disability 43(1): 112-124.

The present study sought to investigate experiences of fathers of young children with autism spectrum disorder (ASD) aged between 2½ and 6 years attending an ASD-specific early intervention centre. Fathers experienced elevated levels of parental stress and elevated depressive symptoms. Findings from this study provide further insight into the fathering role. The need for further research to explore practical implications to better support fathers is discussed.

Young Carers

Younger Caregivers of Stroke Survivors Experience Personal Growth through Caregiving

Mathews, M., et al. (2018). "Abstract TP383: Younger Caregivers of Stroke Survivors Experience Personal Growth through Caregiving." Stroke 49(Suppl 1)

This study focused on quality of life (QOL) of the young caregivers (YCG) of stroke survivors. The Retreat and Refresh Stroke Camp (RRSC), offers respite, opportunities to develop new relationships, networking, sharing and education. Results indicate it played a role in improving the self-worth, confidence, and feelings of appreciation of CG. Camp Directors will use information from this study to develop strategies to improve CG freedom, money management, and general support.

“I Didn’t Expect to Learn as Much as I Did”: Rewards of Caregiving in Young Adulthood

Pope, N. D., et al. (2018). Journal of Adult Development.

This study explored the gains experienced by family caregivers in young adulthood. Analysis revealed four themes concerning gains experienced by young adult caregivers: a strengthening of family relationships, character growth, personal satisfaction in the care provided, and material benefit. This study sheds some understanding on rewards experienced by a subgroup of family caregivers who has received little attention— young adult caregivers.

Disclaimer

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