RESEARCH SNAPSHOT

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

Enhancing support for the mental wellbeing of parents of children with a disability: Developing a resource based on the perspectives of parents and professionals


This study developed a mental wellbeing resource specifically for parents and carers of children and adolescents with a disability. Key information areas for the resource were information about parent/carer wellbeing; understanding the barriers to wellbeing, including lack of support, being unable to ask for help, being isolated from the community, and having insufficient time or income to spend on self; suggestions on how to organise respite; and opportunities for increasing wellbeing.

Information seeking by parents of children with physical disabilities: An exploratory qualitative study


The aim of this study is to describe how parents of children with physical disabilities search for and evaluate information. Results showed peers played an important role in information provision and were the preferred source. There was a general preference for closed Internet communities for peer contact. Parents use different sources for different information needs, and evaluate information by comparing them. Healthcare professionals and parents can support each other in locating and evaluating information.

Time use of parents raising children with severe or profound intellectual and multiple disabilities


The aim of this study was to examine the total time use of mothers and fathers raising children with profound intellectual and multiple disabilities (PIMD) and compare it with the time use of parents of typically developing children. The study shows that the parents of children with PIMD have to spend a significant amount of time on care tasks and have on average 1.5 h less free time per day than parents of typically developing children. This is a striking difference, because leisure time can substantially contribute to well-being.

“How could I have done this?” Thoughts of mothers of children with fetal alcohol syndrome


Biological mothers of children with fetal alcohol syndrome (FAS) must cope with the struggles of parenting a child with special needs with the knowledge that their children’s problems are due to their alcohol use during pregnancy. The group of mothers studied, understood their use of alcohol during pregnancy through reliance on the disease model, inaccurate or incomplete knowledge of the consequences of drinking during pregnancy, the advice of others, and a lack of awareness of the pregnancy.
Autism Spectrum Disorder

Circle of Security intervention for parents of children with autism spectrum disorder


Circle of Security is an attachment-based parenting intervention that aims to promote secure parent–child attachment relationships. This study explored whether this intervention resulted in increased attachment security (assessed before and after completing the intervention) for caregiver–child dyads with Autism Spectrum Disorder. Results found one dyad shifted from avoidant to secure whilst the other dyad remained secure across time with some changes in behavioural dimensions.

The early intervention message: Perspectives of parents of children with autism spectrum disorder


Explored parental perspectives on the early intervention (EI) message for families of children with autism spectrum disorder. Three central themes were identified: parents' initial perceptions of EI following their child's diagnosis; positive and negative consequences of the EI message; and parents' perspectives on life after EI. Results indicated that parents were aware of the importance of EI. Although this provided parents with hope immediately post-diagnosis, it also placed pressure on parental decision-making.

Biographical disruption: Experiences of mothers of adults assessed for autism spectrum disorder


Explored the experiences of parents whose sons or daughters are diagnosed with autism spectrum disorder (ASD) during adulthood. Mothers did not experience disruption around the assessment itself, as it was simply another assessment for their son or daughter and was thus a biographical continuity. Mothers experienced disruption post-diagnosis, as an ASD diagnosis did not result in additional support, and found this greatly frustrating. There is an unmet need for post-diagnostic support among adults diagnosed with ASD.

Parenting, autism spectrum disorders and inner journeys


The study investigated parental perceptions of Early Intervention services for children with significant disabilities. It describes how parents experience assessment, diagnosis and education, and explores the potential of utilising a parental lens in grasping these perspectives. Results suggest that we need to explore what is needed by parents according to those parents, by acknowledging parent voice.

Remembering parents in parent-mediated early intervention: An approach to examining impact on parents and families


Aims to advance the discussion regarding meaningful outcomes of early intervention for children with autism spectrum disorder. The growth of early intervention approaches for autism spectrum disorder includes both therapist-driven and parent-mediated interventions. The majority of research focuses on promoting child outcomes with less emphasis on family and parent outcomes. Increased attention to family outcomes that are of value to families is needed to develop interventions in community settings.

Interventions that target improvements in mental health for parents of children with autism spectrum disorders: A narrative review


Examined improvements in the mental health of parents of children with ASD. Treatment produced medium to large effect sizes with improvements in stress and general health, and reductions in depression and anxiety. Interventions that appeared promising included: Stress Management and Relaxation Techniques, Expressive Writing, Mindfulness-Based Stress Reduction, and Acceptance and Commitment Therapy.
Mental Health

‘Not a good person’: Family stigma of mental illness from the perspectives of young siblings


This study examined family stigma of mental illness in child and youth mental health. From the analysis, young siblings had predominately negative experiences, struggled with making sense of their brother or sister and the family as ‘flawed’ against the mental illness as ‘bad’ and experienced considerable family stress and overt family stigma. Current practice theories fail to consider the complexity of these factors and, in doing so, fail to adequately explain the nature and extent to which stigmatization occurs for immediate family members.

Does group intervention have benefits on expressed emotion and social support in carers of persons with first episode psychosis?


This study evaluated the effectiveness of a 7-session group intervention among caregivers of patients with first episode psychosis. Carers in the intervention group reported reduction of expressed emotion and improvements in social support at a one-month follow-up assessment. However, these benefits were not sustained at the three-month follow-up. Overall, both groups showed significant changes in all outcome variables over the time period.

Caregiver burden in older adults with bipolar disorder: Relationship to functionality and neuropsychiatric symptoms


Aimed to describe which factors increase caregiver burden among caregivers of elderly bipolar disorder outpatients. Potential treatable and modifiable factors associated with caregiver burden could be caregivers’ depression, anxiety, and medical comorbidities, as well as support for caregivers in terms of services and social relationships.

Chronic Condition

Caring for individuals with chronic illness and minor depression: Latino perceptions of caregiver burden


In the US, Latinos are burdened with increasing rates of chronic conditions and have the highest uninsured rates in the country. Growth of the Latino community coupled with an aging population may place increased stress on health care systems. This paper explores the impact of caregiving on those providing support to individuals with co-morbid chronic disease and minor depression. Highlights the influence of caregiving on financial insecurity, balancing competing demands, increased emotional distress, and the role of community.

Couples coping with cardiovascular disease: A systematic review


This article focuses on how couples cope with one partner’s cardiovascular disease (CVD) diagnosis. Principal implications of this review’s findings relate to our fields’ need to provide more care focused on dyads, rather than individual patients, adopt an integrated model in health care, and conduct systemic, longitudinal research to gain a better grasp on how coping changes over time. Doing so will serve to better equip providers in the support of patients and partners living with CVD.
Serious/Terminal Illness

**Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important**


Aims to gain a deeper understanding of elements of end-of-life care that consumers consider most important within the hospital setting. Several overlapping patient and family themes were identified. Consumer narratives help to provide a clearer direction as to what is important for hospital end-of-life care. Systems are needed to enable optimal end-of-life care, in accordance with consumer priorities, and embedded into routine hospital care.

**Family rituals, financial burden, and mothers’ adjustment in pediatric cancer**


In this study, we aimed to determine if family ritual meaning moderates the relationship between financial burden and anxiety and depression symptoms among mothers of children with cancer. Current findings suggest that high levels of perceived family ritual meaning may constitute a protective factor against the effect of financial burden on mothers’ anxiety symptoms. Promoting family ritual meaning might be an effective approach to reducing anxiety symptoms of mothers of children with cancer in the context of financial burden.

**Quality of life and burden in family caregivers of patients with advanced cancer in active treatment settings and hospice care: A comparative study**


The aim of this study was to evaluate caregiver burden and Quality of life (QoL) in active treatment settings and hospice care for family caregivers of advanced cancer patients. Future research needs to further investigate the complexities of caregivers’ needs, especially in the emotional and mental domains, and offer effective, clinically-proven interventions.

**Communications with health professionals and psychological distress in family caregivers to cancer patients: A model based on stress-coping theory**


The first aim of this research is to investigate the relationship between communication with health professionals and psychological distress in family caregivers. The second aim is to investigate the mediating effects of self-efficacy in this hypothetical model. This study indicates that as a coping resource, self-efficacy in health information seeking, plays a significant role in reducing the effects of negative communication with health professionals on psychological distress in family caregivers.

**Quality of life and burden in family caregivers of patients with advanced cancer in active treatment settings and hospice care: A comparative study**


Aimed to evaluate caregiver burden and quality of life (QoL) in active treatment settings and hospice care for family caregivers of advanced cancer patients, using the Medical Outcomes Study Short Form and the Caregiver Burden Inventory. The hospice group reported significantly lower QoL scores in mental component score and higher scores in general health subscale and in physical component score. Future research needs to further investigate the complexities of caregivers’ needs, especially in the emotional and mental domains.
Aged & Dementia

Quantifying the unmet needs of caregivers of people with dementia: A critical review of the quality of measures


The array of demanding tasks carried out by caregivers of people with dementia have significant negative impacts on their physical, mental and social well-being. Needs assessment allows individuals to indicate the extent to which their needs across different areas have or have not been met, allowing for estimations of the prevalence of needs and the extent to which help is required. There is a clear need to develop a psychometrically rigorous instrument to identify the unmet needs of caregivers of people with dementia.

Continuity of home-based care for persons with dementia from formal and family caregivers’ perspective


This paper presents caregivers’ descriptions of collaboration in home-based dementia care and explores whether this collaboration inhibits or enables continuity of care and the use of the statutory individual plan. Results reveal dynamic positions in collaborative practice and discrepancies in descriptions of practices and the needs of the person with dementia. To ensure continuity of care, caregivers must be aware of their positions and discuss expectations for information flow, involvement and care responsibilities.

Fishing for answers: Couples living with dementia managing trouble with recollection


This study focuses on instances where the spouse with dementia is unable to recollect information that she is presupposed to know. Two conclusions were found: different expectations of what is, or should be, common ground may cause communicative problems and distress and; spouses without dementia may use fishing techniques as a way of managing problems regarding recalling knowledge. By adopting a ‘we-perspective’ approach, social workers can make a difference for couples and families living with dementia.

The relationship between family functioning and caregiving appraisal of dementia family caregivers: Caregiving self-efficacy as a mediator


The aim of this study was to explore caregiving self-efficacy as a mediator for the association between family functioning and caregiving appraisal of dementia family caregivers in Taiwan. Our findings provided preliminary evidence for health professionals recommending that future studies should assess the family dynamic and health problems of caregivers, and develop appropriate family-centred interventions that focus on strengthening interfamily support and respite services to alleviate caregiver burden.

Staff factors contributing to family satisfaction with long-term dementia care: A systematic review of the literature


Aimed to evaluate staff factors that contribute to families’ satisfaction with ongoing care provision for relatives with dementia in long-term care. Findings highlighted three areas: staff interaction with families; staffing organisation and composition; and staff interaction with clients and quality of care. Staff training should focus not only on staff education but also on establishing effective relationships with both clients and families.

Understanding informal carers’ experiences of caring for older people with a hip fracture: A systematic review of qualitative studies


Aims provide direction for research, policy and practice. A core theme of ‘engaging in care: struggling through’, was identified. Tensions exist in negotiations with complex health care systems as carers do not feel their expertise is valued and struggle to find and understand information.
TBI/Stroke

Caregiver availability for severe stroke results in improved functional ability at discharge from inpatient rehabilitation

Mirkowski, M., et al. (in press). Disability and Rehabilitation.

Aims to evaluate the predictive capacity of caregiver availability on functional ability at time of discharge from inpatient rehabilitation in individuals with severe first-time stroke. Individuals with a caregiver had significantly higher levels of functional ability at discharge compared to those without. The presence of a caregiver at time of discharge from inpatient rehabilitation is predictive of significantly higher functional ability at discharge in individuals with severe stroke.

The experience of patients with ABI and their families during the hospital stay: A systematic review of qualitative literature


The purpose of this review was to compile and synthesize literature on the experience of patients with acquired brain injury (ABI) and their families during the hospital stay. Patients had negative perceptions of the rehabilitation environment and a perceived need for information. Findings on the family experience included difficulty adjusting after the patient's injury, a desire to be involved in the patient's care, mixed feelings about staff support and a high perceived need for information.

Family caregiver adjustment and stroke survivor impairment: A path analytic model


The purpose of this study was to examine the association between stroke survivors’ impairment and caregiver depression, and determine the possible mediating effects of caregiver negative problem-orientation, mastery, and leisure time satisfaction. Caregivers at risk for depression reported a negative problem orientation, low caregiving mastery, and low leisure time satisfaction. The findings provide empirical support for the Pearlin’s stress model and emphasize the importance of targeting mediators in health promotion interventions.

Recognition & Support of Carers

Supporting the supporter: Social support and physiological stress among caregivers of children with severe disabilities


This study explored whether short-term supportive interactions between parents of children with disabilities and members of their supportive network influenced their physiological stress responses. Parents experienced decreases to their physiological stress, though the quality of the support played a key role in determining how beneficial the interaction was. These results suggest the importance of considering support quality when examining the influence of social support on physical outcomes for support recipients.

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


Social support has been described as a vital resource for families with children with disability. Although the benefits of social support have been described, little is known about the utilisation patterns in families of young children with autism spectrum disorder (ASD). This study examined the utilisation and usefulness of social support. Child, family, and service variables related to social support were explored.
“The Church of Online Support”: Examining the use of blogs among family caregivers of persons with dementia


The study used blogs by caregivers of persons with dementia to explore how caregivers used this medium as part of their experience. Four themes emerged: social support through communication and engagement, information gathering and seeking, reminiscing and legacy building, and altruism. By understanding the ways caregivers of people with dementia use social media as part of the caregiving experience, family nurses can develop interventions and services to improve caregiver burden and quality of life.

Do spouse caregivers of young and older persons with dementia have different needs? A comparative study


Aimed to explore the needs of spouse caregivers of persons with dementia (PWD) and then to compare them based on the PWD's age at disease onset. The results demonstrated that the majority of needs are the same for the two groups of spouse caregivers. However, some differences emerge, with the spouse caregivers of PEOD (early onset) expressing a greater number of needs.

Carer Health & Wellbeing

Parent, carer, person: Future plans and the identities of parent carers for people with disabilities


Parent carers are often central in future planning for their children with disability; however, little is known about the implications of planning for parents’ futures and aspirations. In understanding these, parents’ own identities are important, but how these identities intersect with their planning is not well understood. This study explored how parents were positioned in discussions about planning. Three positions among parents were highlighted: carer, parent, and person; representing multiple, intersecting identities.

The Family Time Squeeze: Perceived family time adequacy buffers work strain in certified nursing assistants with multiple caregiving roles


This study examined how certified nursing assistants, (CNAs), with unpaid family caregiving roles for children (“double-duty-child caregivers”), older adults (“double-duty-elder caregivers”), and both children and older adults (“triple-duty caregivers”) differed from their nonfamily caregiving counterparts (“workplace-only caregivers”) on four work strain indicators. Perceived family time adequacy constitutes a salient psychological resource for double-duty-child and triple-duty caregivers’ family time squeezes.

Parental coping with adolescent developmental disabilities in terms of stress, sense of coherence and hope within the Druze community of Israel


This study sought to compare Druze parents of adolescents with and without developmental disabilities (DD) in the context of Druze traditions and beliefs and whether they may lead to better coping by parents of a child with DD. The results of the study partly contradict the assumption in the limited literature about Druze that they may cope better with life stressors as a result of their traditions and beliefs. The results also indicate the need for further research and culturally-based intervention programs.
Subjective happiness among mothers of children with disabilities: The role of stress, attachment, guilt and social support


Parenting a child with disabilities might affect the happiness of the mothers. This study aims to examine the impact of risk factors on the mother’s adaptation happiness. The findings of the current research show direct and indirect associations of risk factors with happiness and the role of general stress and feelings of guilt as mediators. This study stresses the importance of attachment and social support to happiness and sheds light on the unique role of guilt in promoting or inhibiting happiness.

Caregiver needs and stress in caring for individuals with fetal alcohol spectrum disorder


This study considered the needs of caregivers supporting individuals with fetal alcohol spectrum disorder (FASD) and whether they are associated with caregiver stress. Caregivers of individuals with FASD have multiple areas of need and concern, and experience high levels of stress. Reducing demands on caregivers and providing resources may help reduce caregiver needs and stress, particularly for those caring for adolescents and adults, and those with lower incomes.

The effects on carer well-being of carer involvement in cognition-based interventions for people with dementia: A systematic review and meta-analysis


Aims to investigate the effects on carer well-being of carer involvement in cognition-based interventions (CBIs) for people with dementia. The collateral benefits for carers have potential implications for the importance of CBIs in service delivery and may contribute to cost effectiveness. However, there remains a lack of quality and consistency of research in this area.

Social Inclusion, Relationships & Community Participation

Social support and coping strategies of parents raising a child with autism spectrum disorder


Explored the psychological and social needs of parents with a child with autism spectrum disorder (ASD). More mothers reported engaging in emotion-focused strategies and accessing social support for emotional and practical support. Traditional gender roles emerged as a significant factor in mothers’ and fathers’ coping strategies.

Social networks, social support and social negativity: A qualitative study of head and neck cancer caregivers’ experiences


Caregivers of head and neck cancer patients can experience considerable stress as a result of their caring activities. Supportive relationships can protect caregivers from psychosocial strain. Caregivers were interviewed about their experiences of accessing social support from their social networks; difficulties that they experienced accessing this support; and strategies that they used to address these difficulties. Results suggest that head and neck cancer caregivers strongly value social support, but can find it difficult to obtain.

It’s interpersonal: Family relationships, genetic risk, and caregiving


Considers family relationships across the life course: in early life, focusing on disease prevention; leveraging genetic risk information and relationships to motivate health-promoting behaviours; and in later life, focusing on informal caregiving; identifying characteristics of those most vulnerable/resilient to caregiver stress. The researcher’s personal experiences in this area are discussed. The study highlights the significance of understanding the multiple ways in which families adapt and cope with risk and disease diagnoses.
Carers & Gender

“I received a leaflet and that is all”: Father experiences of a diagnosis of autism


The study considered parental perceptions of the process of diagnosis of childhood autism. Several themes were identified: strong initial emotional response and a range of immediate anxieties about the future, struggle to gain a diagnosis; anger in response to insensitive delivery of diagnosis together with insufficient information at the time and lack of support afterwards. Fathers experienced a range of significant challenges during a diagnostic process in which most felt unsupported. Service provision should be more gender-differentiated.

Young Carers

Caregiving youth knowledge and perceptions of parental end-of-life wishes in Huntington’s disease


This study sought to explore caregiving youth knowledge of parental end-of-life (EOL) wishes and their willingness for EOL discussions. Caregiving youth, who have a parent with Huntington’s disease (HD), discussed their knowledge of their parent’s living will and durable power of attorney for health care, and willingness to talk with the parent about EOL choices. Findings suggest HD patients and caregiving youth need support for open discussion, and could benefit from educational programs and support groups.

Psychosocial well-being of young people who participated in a support group following the loss of a parent to cancer


This study explored the psychosocial well-being of young people who have lost a parent to cancer. Significant positive changes were found regarding a sense of meaning in their future life and life satisfaction. The helpfulness of the group was assessed as high/very high and the group brought a valuable fellowship with others in a similar situation. Universality and beneficial interactions were reported and strengthened psychosocial well-being developed over time.

Former Carers

When caregiving ends: The experiences of former family caregivers of people with dementia


This study examines the health of former family caregivers and describes their experiences following the death of a care recipient with dementia. Three overarching themes emerged from the data: sleep disturbances, changes in health status, and learning to live again. Despite relief from caregiving duties, sleep disturbances in former family caregivers persisted for as long as 10 years post-caregiving. Results suggest that there may be long-term effects of caregiving on health that persist beyond the first year post-caregiving.

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