Rebecca Mutch, K., et al. (in press). Disability and Rehabilitation.

**Aims**
To explore the lived experience of partners of people with NMO and to investigate potential carer burden in this population. Three themes influenced partners' quality of life: role/relationship; it's all about them; and the impact of NMO. Participants regarded themselves as partners rather than carers whom require assessment and support for their emotional and health well-being. Health-care professionals need to acknowledge the role partners play in the dynamics of the family unit, through discussion and inclusion.

**Fatigue in the mothers of children with cerebral palsy**
Garip, Y., et al. (in press). Disability and Rehabilitation.

Aims to evaluate fatigue in the mothers of children with cerebral palsy (CP), and to determine its associations with clinical parameters of CP, depression and quality of life (QoL). Our findings indicate that fatigue levels of mothers with CP children are higher than those with healthy children and associated with depression and deterioration in QoL in terms of physical, social and emotional functioning. This should be considered while designing a family centred rehabilitation programme for children with CP.

**Intellectual Disability**


This study reports what parents perceive to be a positive aspect of parenting their child, as currently what constitutes a ‘positive’ is unclear. Seven key themes were identified: an increased sense of personal strength and confidence, changed priorities, greater appreciation of life, pleasure in the child’s accomplishments, increased faith/spirituality, more meaningful relationships and the positive effect that the child has on the wider community. The positive aspects identified consist mostly of meaning-focused coping strategies.


The purpose of this study was to measure the contribution of group membership (having or not having autism) and maternal factors (self-efficacy and participation) to the participation of children with ASD in everyday situations. The group membership was found to be the main predictor of child participation. Mothers’ participation and self-efficacy explain the notable proportion of child’s participation. Results may provide new information on child participation and its reliance on mothers’ participation and self-efficacy.
Effectiveness of parent training activities on parents of children and young adults with intellectual or developmental disabilities


Parent Training and Information Centres educate and empower parents of children and young adults with intellectual or developmental disabilities to advocate for services, especially low-income and minority families. However, little research has examined whether Parent Training and Information Centres are effective. Parents demonstrated significant increases with respect to empowerment, special education knowledge, and satisfaction with services. Minority and low-income families reported the greatest increases.

Mental Health

Young people living with mental illness: Managing parental involvement


This paper explores, from the perspectives of young people living with mental illness, how they manage parental support and involvement. Young people reported shaping parental involvement using a combination of facilitation, compliance and resistance. Their actions were determined by a complex alignment of their wish for parent involvement, perceived potential to influence their parents, and ability to communicate their needs.

Physical health and mental illness: Listening to the voice of carers


Aims to present views and opinions of carers regarding physical health of the people with mental illness they care for. Two main themes were interaction between physical and mental health; and, carers’ own physical and mental health. Participants described the impact of mental illness and its treatments on physical health, including their own. Carers are acknowledged as crucial for the delivery of high quality mental health services. Hearing their views and opinions is essential.

Perception of family emotional climate by family members of persons with schizophrenia


This study aims to explore the relation between family members of schizophrenia persons’ personality traits and Family Emotional Climate (FEC). The findings highlight that caregivers’ personality traits seem to influence the FEC. While caregivers’ perception of FEC is positive in this study, those in the higher education group seem to have a better perception of FEC indicating that education also may influence FEC.

Longitudinal and reciprocal relationships between depression and disability in older women caregivers and noncaregivers


Depressive symptoms and disability each increase the risk of the other, yet few studies have examined associations between these conditions, or periods longer than 3 years. These associations may differ in older caregivers. Caregivers did not exhibit longitudinal or reciprocal relationships between depressive symptoms and disability observed in noncaregivers. It is possible that older women caregivers are buffered by better physical condition or social interactions related to caregiving activities.

Acceptance and efficacy of interventions for family caregivers of elderly persons with a mental disorder: A meta-analysis


The aim of this study was to conduct an extended meta-analysis of the efficacy and acceptance of supportive interventions for alleviating depressive symptoms in family caregivers of elderly relatives with a mental disorder, including dementia, and secondly, to analyse intervention characteristics as potential moderators of the efficacy and acceptance of these interventions. Individual customization of intervention components might enhance efficacy.
Analysis of the components of a cognitive-behavioural intervention administered via conference call for preventing depression among non-professional caregivers: A pilot study


Aims to assess the feasibility/acceptability of a preventive cognitive-behavioural intervention implemented via conference call for caregivers, and secondly to conduct a preliminary assessment of the efficacy of the behavioural activation component (BAC) alone compared to the complete cognitive-behavioural intervention (CBC). The results support the feasibility of the intervention. Moreover, the BAC intervention was non-inferior to the CBC intervention for reducing depressive symptoms.

The mental health and mortality impact of death of a partner with dementia


This study describes the health of people caring for a partner with dementia in the year before and after loss of this partner, compared with other bereavements. In the year before bereavement, partners of individuals dying with dementia experience poorer mental health than those facing bereavement from other causes, and their partner is less likely to receive palliative care. In the year after, individuals whose partner died with dementia experienced some attenuation of the adverse health effects of bereavement.

Drug/Alcohol Dependency

The emotional health and well-being of Canadians who care for persons with mental health or addictions problems


The purpose was to examine the emotional health and well-being of Canadian caregivers of persons with significant mental health or addictions problems. We assessed by care-receiver condition type, levels of caregiver stress and methods particularly for reducing stress among caregivers. Caregivers with mental health or addictions problems were more likely to report caregiving stress and that they felt depressed, tired, worried or anxious, overwhelmed; lonely or isolated; short-tempered or irritable; and resentful.

Depression, distress, burden and social support in caregivers of active versus abstinent addicts


Focuses on the relationships between clinical, demographic, and psychological variables, such as depression, distress, burden and social support in informal caregivers of addicts. Results showed significant associations between burden and patients’ number of detoxifications, patients’ arrest due to substance abuse, distress and social support. Caregivers of addicts would benefit from interventions that increase social support, decrease burden, depression and distress, particularly, those who care for non-abstinent addicts.

Dimensions of treatment quality most valued by adolescent substance users and their caregivers


Aims to examine how adolescent substance users (ASU) and their caregivers perceive treatment quality of professional psychologists, and secondly, to determine how these perceptions align with expert-derived definitions of ASU treatment quality and dimensions of perceived quality used in other disciplines. 3 dimensions of perceived treatment quality were identified: therapeutic relationship, provider characteristics, and treatment approach.
**Chronic Condition**

Caregivers reflecting on the early days of childhood cancer


Examines the experiences of primary caregivers of children with cancer through diagnosis and early treatment, investigated when their child is in remission. The concept of neo-normal represented caregivers’ responses to having a child with cancer. Conceding to the disempowered position facilitated new ways to be a caregiver of a child with cancer. Findings illustrate the social processes and cultural context in which caregivers construct new normalising strategies as they transition through their child’s illness.

Lived experiences of parents caring for a child with a life-limiting condition in Australia: A qualitative study


Aims to provide an in-depth exploration of the prevalent lived experiences of parents who are currently providing care for a child with a life-limiting condition in Australia. Four key themes represented the experiences of parents: trapped inside the house, the protector, living with the shadow and travelling a different pathway. These themes highlight the demand for physical and emotional support beyond what is currently offered and call for carefully planned support services and other societal initiatives.

A systematic review on the factors associated with positive experiences in carers of someone with cancer

Young, J. and A. Snowden (in press). *European Journal of Cancer Care*

Aims to identify the factors associated with positive experiences in non-professional carers of someone with a cancer diagnosis. Analysis identified four overarching attributes: “gender,” “personal resources,” “finding meaning” and “social context.” Despite the challenges associated with caring, this combination of internal and external factors enabled some carers to report positive experiences related to caring. This knowledge may be clinically helpful when designing supportive interventions.

**Serious/Terminal Illness**

Family caregiving in Japan: The influence of cultural constructs in the care of adults with cancer


This study aimed to gain insight into perceptions and experiences surrounding caregiving, acknowledging the unique role of cultural beliefs in shaping behaviour. Several major categories were identified, representing rarely reported cultural constructs of high cultural value for the Japanese. The Japanese cultural construct involving the strong relationship to family lineage and spiritual connection to past and future generations is helpful in understanding these categories.

Identities in transition: Women caregivers in bereavement


This study of bereaved women caregivers explored their lived experiences in the postcaregiving phase. One central theme emerged and suggested that the experience of caregiving had an effect on the caregivers’ identities, which then influenced their bereavement processes and experiences.

Negotiation of dialectical contradictions by parents who have experienced the death of a child


This study examines how bereaved parents experience communicating with individuals in their social network. Parents experienced two dialectical contradictions: between the physical absence of their child and the continuing presence and emotional bond with their deceased child; and between being open or closed when deciding whether to talk about the deceased child to others.
The Life Tape Project: Increasing family social support and symbolic immortality with a brief existential intervention for cancer patients and their families


This article presents the Life Tape Project, developed to help families support patients in dealing with fears of death and dying. It is designed to help bring families closer together, increases communication, and acts as an existential intervention leading to greater sense of legacy, meaning, self-awareness, identity, and connection. The article describes symbolic immortality, an aspect of existential coping, to illuminate how existential and social support factors can work together to benefit patients and their families.

Dare to ask children as relatives! A qualitative study about female teenagers’ experiences of losing a parent to cancer


Nurses must pay attention to teenager altered lives when a parent receives treatment for cancer. The aim of this study was to describe female teenagers’ experiences of losing a parent to cancer. Four categories were highlighted: sadness, fear, anger, and comfort. Blogs served as a tool for gathering strength for teenagers in their difficult circumstances. The results show that female teenagers need information and support to be able to move on after the traumatic experience. Support needs to be in line with the children’s individual needs.

The caregiver burden in male romantic partners of women with non-metastatic breast cancer: The protective role of couple satisfaction


We examined the evolution of the subjective burden of romantic partners caring for women with non-metastatic breast cancer and investigated the moderating role of couple satisfaction on caring stress. Results showed that subjective burden decreases over time and that the couple satisfaction largely explains it above and beyond other influential variables. Partners dissatisfied with their couple relationship are especially vulnerable to the stress of caregiving.

Aged & Dementia

A systematic review and meta-analysis comparing carer focused and dyadic multicomponent interventions for carers of people with dementia


The aim of this study was to compare the efficacy of two approaches: multicomponent interventions that focus on working with the carer, and dyadic interventions that work with both the carer and the person with dementia. Results suggest multicomponent interventions can reduce depressive symptoms, improve quality of life, reduce carer impact, and reduce behavioural and psychological symptoms of dementia as well as caregiver upset with these symptoms.

“It was then that I thought ‘whaat? This is not my Dad’: The implications of the ‘still the same person’ narrative for children and young people who have a parent with dementia


This article explores the experiences of people who had a parent with dementia. Analysis revealed challenges related to the construction of their parent as the same person. This was not seen as helpful. Furthermore, expectations that they will behave and feel towards that parent as they did before are a source of distress in what is already a challenging situation. This paper highlights the need to equip young people with support that acknowledges that their parent may well be drastically different to the Mum or Dad they previously ‘knew’.

www.carersnsw.org.au
Predictors of caregiving burden: impact of subjective health, negative affect, and loneliness of octogenarians and centenarians


This study aimed to: determine whether octogenarian and centenarian care recipients' self-report on physical, social, and emotional status are different from caregivers’ reports; to assess associations between octogenarian and centenarian care recipients' poor physical, social, and emotional status and caregiver burden; and to determine which report, the care recipients' self-report or caregivers’ report, about the participants’ physical and emotional status predicted more accurately levels of caregiver burden.

Dementia spousal caregivers and past transgressions: Measuring and understanding forgiveness experiences


The transition from ‘wife’ to ‘caregiver’ for a cognitively impaired husband can be overwhelming. Communication patterns change and small conflicts can grow, bringing angry feelings and new burdens. Engagement with forgiveness processes may benefit wives by lowering resentment over past tensions, restoring trust, and enhancing the overall caregiving experience. This study aims to better understand this population’s experience with forgiveness when other contextual factors were likely to influence this process.

Managing Your Loved One’s Health: Development of a new care management measure for dementia family caregivers


This article describes the development and preliminary cultural tailoring of a comprehensive, caregiver-centred measure, Managing Your Loved One’s Health (MYLOH), based on a set of health care management domains endorsed by both providers and caregivers. MYLOH can be used to guide conversations between clinicians and caregivers around health care management of people with dementia, as the basis for targeted health care coaching, and as an outcome measure in dementia care management interventions.

‘And so I took up residence’: The experiences of family members of people with dementia during admission to an acute hospital unit

de Vries, K., et al. (in press). Dementia.

It is estimated that a quarter of acute hospital beds are in use by older people with dementia at any one time. In this article, we present the results regarding experiences of supporting an admission of a person with dementia to an acute hospital unit in New Zealand. For all family members, the desire to support the person with dementia during their admission was at the forefront and was their primary focus. The theme, ‘And so I took up residence’, exemplifies fully the experiences of all of the family member participants.

The impact of anticipatory grief on caregiver burden in dementia caregivers


This paper explored anticipatory grief (AG) in the context of dementia, as unique, due to the progressive deterioration of both cognitive and physical abilities. Results suggest that grief may be an important yet understudied aspect of the caregiving experience. It is likely that consideration of grief in future conceptualizations of caregiver burden can lead to better support for caregivers and more accurate predictions of outcomes.
Family members’ needs and experiences of driving disruption over time following an acquired brain injury: An evolving issue

Liang, P., et al. (in press). Disability and Rehabilitation.

Family members often assume the role of driver for individuals who are not driving post-acquired brain injury (ABI). This study aims to understand the needs and experiences of family members over time during driving disruption following an ABI. Four phases of driving disruption were revealed: Wait and see, Holding onto a quick fix, No way out, and Resolution and adjustment. The phases described a process of building tension and a need for support and resolution over time.

Family members’ narratives of lifespace: Mapping changes before and after a brain injury causing driving disruption


The geographic area in which people travel and conduct their activities is known as lifespace. This study aimed to describe the changes in family members’ lifespace after brain injury and understand their subjective experiences through interacting with maps during narratives. Data analysis revealed four themes: I will do everything for him or her; Trying to fit it all in; We spend all our time together now; I need to also care for myself. Highlights the importance of understanding both quantitative and qualitative aspects of lifespace.

Parents’ experiences of their child’s return to school following acquired brain injury (ABI): A systematic review of qualitative studies


Examined parents’ experiences during their child’s return to school following acquired brain injury. Ten themes were identified, in three clusters: influencing factors (environment, school, parent and child factors); features of interaction (information, communication and collaboration); and quality levels of outcome (conflict, coping and construction of new roles and identities). Parents’ experiences are influenced by the quality of information, communication and collaboration between the school, health professionals and the family.

Guidance for community-based caregivers in assisting people with moderate to severe traumatic brain injury with transfers and manual handling: Evidence and key stakeholder perspectives

Piccenna, L., et al. (in press). Health & Social Care in the Community.

Adults with moderate to severe traumatic brain injury (TBI) rely on assistance from paid and unpaid caregivers upon return to the community. These adults are highly dependent on caregivers for transfers and manual handling tasks. This study considered key issues in community-based manual handling following TBI. Three guidelines were identified. Development of comprehensive guidance for caregivers in transfers and manual handling in people with moderate to severe TBI living in the community is a hidden but important priority.

Family needs at a post-acute rehabilitation setting and suggestions for supports


Aims to explore the perceived needs, obstacles to services, psychological distress and social problem-solving abilities of family members of persons with ABI. Family members who do not provide daily care are still impacted by the neurobehavioural changes that progress throughout the long-term, post-acute community phase. This study offers suggestions regarding an effective methodology for assessing family needs and recommends accessible and practical supports.
Stroke patients’ and informal carers’ experiences with life after stroke: An overview of qualitative systematic reviews

Lou, S., et al. (in press). Disability and Rehabilitation.

This paper looks at patients’ and informal carers’ experiences with rehabilitation and life after stroke following discharge. Stroke causes profound disruption of life as known, and both patients and carers must engage in a process of adapting and rebuilding a post-stroke life and identity. This process of rehabilitation is described as temperamental and unstable rather than progressive. Five key experiences in this process are identified: autonomy, uncertainty, engagement, hope and social relations.

Recognition & Support of Carers

Impact of caring for children with medical complexity on parents’ employment and time


This study examined parental care of children with medical complexity (CMC) in terms of time spent providing care and impacts on employment and career. Caring for CMC frequently impacts employment and careers of caregivers and spouses. Employed and non-employed caregivers invest substantial time in care. Research on CMC should include indirect costs of family care in terms of employment, income, and time.

Transnational caregiving for my father: An opportunity and a blessing


Transnational caregiving can be daunting, yet often brings out strengths of the caregiver that they may not have been aware of. Transnational caregiving is also a blessing, in that one can still continue to provide care for a loved one over the barriers of geographical distance. To transform what often is a challenging situation into a blessing, a fresh eye is needed to seek different ways of fulfilling the needs of the loved one: How can the caregiver, in his or her individual capacity, make a difference in the quality of life of the family member?

Assessing caregivers’ needs in the workplace: A pilot study


This study asked whether a survey targeting carers in the workplace can identify patterns of relationships between a carer’s strain arising from managing work and direct care activities and either his/her characteristics or the characteristics of the specific caring activities performed. The survey contained three sections: demographic information, subjective and objective state of the carer, and knowledge and use of caregiving services. Findings replicate the belief that knowledge and use of care services can benefit carers.

Carer Health & Wellbeing

The long-term effects of caregiving on women’s health and mortality


Caregivers experience numerous mental and physical health effects from the stress of providing care, but we know little about whether these problems persist in the long term and whether long-term effects differ across caregiving contexts. This study examined the relationship between caregiving and long-term patterns of depressive symptoms, functional limitations, and mortality. We also explored the health effects of caregiving in-home versus out-of-home and by caregiver/care-recipient relationship.

Self-efficacy for controlling upsetting thoughts and emotional eating in family caregivers


Examines self-efficacy for controlling upsetting thoughts through emotional eating by family caregivers of physically and cognitively impaired older adults. Findings replicate previous research demonstrating the relationship between managing cognitions about caregiving and behavioural responses to stressors, and point to the importance of addressing cognitive processes to improve caregiver health behaviours.
Informal caregiving in head and neck cancer: Caregiving activities and psychological well-being


This study quantified the general cancer support activities that long-term carers of head and neck cancer (HNC) survivors engage in; and the relationships between these care activities and psychological well-being. Most carers were comfortable assisting their relative/friend, though more carers felt uncomfortable assisting with HNC-specific support tasks compared with general support tasks. Feeling uncomfortable with head and neck-specific care tasks was a significant predictor of experiencing depression and anxiety.

Social Inclusion, Relationships & Community Participation

Family close but friends closer: Exploring social support and resilience in older spousal dementia carers


Spousal dementia carers have unique support needs; they are likely to disengage from their existing social networks as they need to devote more time to caring as the disease progresses. This paper aims to explore social support as a key component of resilience to identify the availability, function and perceived functional aspects of support provided to older spousal dementia carers. Family and friend support is not always sufficient to facilitate resilience. Support functions facilitate resilience only if they are perceived to match need.

Availability of caregiver-friendly workplace policies (CFWPs): An international scoping review

*Ireson, R., et al. (in press). Health & Social Care in the Community.*

This paper explored the availability of caregiver-friendly workplace policies (CFWPs) within workplaces on an international scale while being observant of how gender is implicated in care-giving. Four main themes were identified: Diversity and Inclusiveness, Motivation, Accessibility, and Workplace Culture. This review narrows the gap in the literature with respect to determining: the workplaces which offer CFWPs, the sectors of the labour force shown to be supportive and the most frequently offered CFWPs.

Living with bipolar disorder: The impact on patients, spouses, and their marital relationship


This study examined the impact of bipolar disorder on patients and spouses individually, and on the marital relationship from the perspectives of both patients and spouses. The research indicated that patients and partners alike struggle with the tremendous impact of bipolar disorder on their lives and on their relationships. Given the high rates of divorce and volatility in these relationships, healthcare professionals can provide emotional and practical support both to patients and spouses on their own, and as a couple in their clinics.

Spirituality & Religion

Religious coping among adults caring for family members with serious mental illness


Investigated the use of religious coping strategies among family members of adults with serious mental illness. Religious coping was associated with more objective carer burden, greater care recipient need, less mental health knowledge, and less receipt of mental health services. Also associated with a positive caregiving experience and greater religious support. Religious coping plays an important role for many carers of persons with mental illness. Such carers may have a high need for mental health education and services.
The faith of primary carers of persons with dementia

This small-scale study investigates the experience of 53 Christian churchgoers in the UK who are or have recently been the primary carers of a relative or friend suffering from dementia. Results reveal how almost all these carers claim to have been supported by their faith, and how far it has been challenged and maybe deepened. Respondents also comment on the role of their local churches. Issues are identified where further research might be beneficial, and where lessons can be learned by the churches.

Faith, work, and reciprocity: Listening to Mexican men caregivers of elderly family members

This study examined the role of Mexican men caregivers of older adults. The results were categorized into three themes: reciprocity in family caregiving, a practical work-oriented attitude toward caregiving, and strong religious faith. Caregiving formed an important part of their masculine role. Stereotypes related to gender and care should be re-examined. Further research is needed to explore gender variations in caregiving, evolving gender roles, and needs for support and services.

Person Centred Approaches/NDIS

Workforce issues in the Australian National Disability Insurance Scheme: Complex support needs ready?

This article raises concerns about NDIS workforce planning issues as they relate to people with intellectual disabilities and complex support needs. A number of challenges to developing and maintaining the skills of the workforce are proposed. If the NDIS is to ensure a workforce ready to support participants with intellectual disabilities and complex support needs, these challenges require immediate action, the absence of which could mean the very real potential of market failure for this vulnerable group.

Person-centredness in the community care of older people: A literature-based concept synthesis

‘Person-centredness’ is a ubiquitous term, employed in modern care services to signify policies and practices that attend to the uniqueness of each individual user. Despite being highly regarded in older adult community care services, there is much ambiguity over its precise meaning. This paper identified 12 common attributes within the broad themes of ‘understanding the person’, ‘engagement in decision-making’ and ‘promoting the care relationship’. A ‘one-size-fits-all’ approach should be discouraged in community care.

Aboriginal Carers

Who cares and does it matter for the labour market? A longitudinal analysis of the labour force status of Indigenous and non-Indigenous carers

Describes the labour market dynamics of Indigenous and non-Indigenous carers, and the extent to which these differ from the dynamics of those who are not carers. The study examines how labour force status changes in association with starting as a carer and exiting from caring. Employment probabilities and labour force transitions are analysed, raising questions about how caring decisions are made within households and the extent to which the costs of caring may differ between Indigenous and non-Indigenous households.
CALD Carers

The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: An interpretive phenomenological analysis

**Munroe, K., et al. (2016). Disability & Society 31(6): 798-819.**

Investigates the experiences of African immigrant mothers living in the UK with a child diagnosed with an Autism Spectrum Disorder (ASD). Four themes were identified: caring for a child we did not expect, the pain of stigma and rejection, frameworks of meaning, and negotiating conflicting cultural beliefs. Conflicts between African cultural beliefs and a western, medical understanding of ASD appeared to create a feeling of cognitive dissonance for the mothers.

What do we know about the attitudes, experiences and needs of Black and minority ethnic carers of people with dementia in the United Kingdom? A systematic review of empirical research findings


This paper considers the experiences, attitudes and needs of caring for someone with dementia in Black and minority ethnic communities in the UK. Several themes and issues were identified: memory loss being viewed as a normal process of ageing, care being perceived as an extension of an existing responsibility, a poor understanding of what support services provide, the influence of migration, the impact of stigma and increased female responsibility.

‘I wanted to come here because of my child’: Stories of migration told by Turkish-speaking families who have a son or daughter with intellectual disabilities


This research focuses on narratives told by Turkish-speaking families about migrating to the UK with a family member with intellectual disabilities. Seeking help for the person with intellectual disabilities in a new country was a central part of migration narratives. The family member with intellectual disabilities was described as being caught up in wider geo-political conflicts. Families continued to face challenges within their own communities and with accessing local services.

LGBTIQ Carers

Psychological trauma and LGBT caregivers: A conceptual framework to guide practice


LGBT adults often face social isolation, discrimination, and victimization, and occasionally they engage in detrimental behaviours such as high alcohol and drug use and risky sexual activity that negatively impacts on psychological/physical health. These risks can affect their overall health and stress the relationship with an older caregiver/recipient-partner following exposure to an acute medical event. This article aims to understand the effect of stressors on LGBT caregiving partners.

Rural Carers

Understanding receptivity to informal supportive cancer care in regional and rural Australia: A Heideggerian analysis


‘Receptivity’ is a new way of understanding the personal and social factors that affect a person living with and beyond cancer, and how these factors influence access to formal supportive care service provision and planning. A cancer diagnosis is a life-changing experience, particularly in regional communities, where survival rates are lower and there are significant barriers to accessing services. Findings revealed that most participants were not referred to, and did not seek, formal supportive care.
Supporting Caregivers of Rural Veterans Electronically (SCORE)


The increasing prevalence of dementia among rural veterans, highlights the improved outcomes possible for caregivers who receive effective support. However, providing these complex interventions in rural areas presents challenges. Internet-based and telephone-based caregiver support can potentially expand access to effective support. This study demonstrates the feasibility and acceptability of using a variety of modalities to deliver caregiver support to a group of largely older, rural, spousal caregivers of veterans with dementia.

Coping with cognitive impairment and dementia: Rural caregivers’ perspectives


Describes how rural caregivers cope with caring for a loved one diagnosed with mild cognitive impairment or dementia. Rural caregivers described their positive experiences in addition to the more commonly explored caregiver experiences related to stress. Coping techniques included: use of social support, engaging in relaxing and physical activity, and cognitive reframing. Caregivers reported strong faith and religiosity, and to a lesser frequency; behavioural changes, checking in with the person via telephone, and joint activity.

Carers & Gender

Nonstandard parental employment schedules and father involvement


This study assesses the impact of nonstandard employment schedules (shift work) on parenting among US fathers of young children in dual-earner couples. Results indicate that employment scheduling mainly shapes the context in which involvement takes place. Compared to dual-earner couples who are each employed during the day, fathers in couples in which at least one parent has a nonstandard schedule tend to care for their children more in the mother's absence. To a more limited extent, they also do more caregiving overall.

‘Because it’s the wife who has to look after the man’: A descriptive qualitative study of older women and the intersection of gender and the provision of family caregiving at the end of life


Explores how gender norms constructed older women’s views about appropriate roles of women and men in providing palliative care for family members. Three themes regarding gender and caregiving were identified: the expectation women will care, women’s duty to care and women’s construction of men in relation to caregiving and illness. The expectation that older women will provide end-of-life care even when experiencing considerable burden is an unacknowledged outcome of gender norms that construct women as caregivers.

From roaring on the hilltop to weeping by the bedside: Protector personas of fathers raising children with autism spectrum disorder


Autism spectrum disorder (ASD) is the most common neurological disorder affecting children in Canada and the communication and behavioural challenges associated with a child's ASD diagnosis make for intense parenting experiences. This article examines how fathers strategically present their identities, or 'personas', as protectors, in relation to raising children with ASD. Fathers exemplify an impactful blend of traditional and modern father ideals through personas that entail tender involvement along with fierce protectiveness.
Gender differences in spousal care across the later life course


Spouses often serve as the primary caregivers to their ill or disabled partners. This study examined the moderating effects of age, gender, and full-time employment on married women’s and men’s receipt of spousal care. Findings showed that among community-dwelling married adults, the gender gap in care was larger among those in middle age (50–65) than it was among those in older age. As women and men aged, the gender gap decreased primarily because men left full-time work and increased time spent caring.

Young Carers

A qualitative evaluation of an innovative resilience-building camp for young carers


Young carers are at increased risk of developing mental health and social problems. This study aimed to pilot a camp-based resilience-building programme for young carers. Two key themes emerged: coping self-efficacy, with subthemes of affect regulation, interpersonal skills, and recognition of strengths and coping ability; and social benefits, with opportunities for respite and social engagement. Participants enjoyed the camp, would recommend it to other young carers, and provided some suggestions to improve future camps.

Don’t forget the siblings: School-aged siblings of children presenting to mental health services show at-risk patterns of attachment


This study assessed the self-protective (attachment) strategies of the siblings of children presenting for psychiatric evaluation and also of the siblings of children drawn from the normative population. School-aged siblings were found to use a broad range of strategies, and the pattern of change from first born to later born involved either a reversal of strategy or a shift to a more complex strategy. The study highlights that siblings of children presenting to mental health services are significantly affected by family relational stress.

Young children's experiences of living with a parent with bipolar disorder: Understanding the child's perspective


Explored the experiences of young children living with a parent with bipolar disorder (BD) and how this impacts on their emotional well-being. Four main themes were identified: perception of parents; knowledge and awareness of BD; managing family life with a ‘bipolar’ parent; and living in a family with BD. Children had candid and insightful discussions about their parent’s BD including symptoms and parenting, and could reflect on how having a parent with BD affected them emotionally and practically.

‘It's different, but it's the same’: Perspectives of young adults with siblings with intellectual disabilities in residential care


Aimed to give voice to young adults whose siblings have an intellectual disability (ID) and are in residential care. Themes included family and sibling relationships and concerns for the future. Dissonances included identifying as ‘one family’ whilst living apart, experiencing guilt while being supportive of the residential placement, and emphasising the normality of the sibling experience whilst also feeling different and isolated. Findings reflect the complexity of sibling relationships when the person with an ID lives in residential care.

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