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Carer Wellbeing and Supports: A review of the literature and directions for research

Centre for Carers Research

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Executive Summary

This research report presents the findings of a study conducted in 2018 at the Centre for Carers Research, Institute for Public Policy and Governance, University of Technology Sydney. The overall objective was to gain an understanding of current research and debates relevant to the focus areas of the *NSW Carers Strategy 2014-2019*, and to draw upon this synthesis to suggest future research directions. Literature published in English between 2008 and 2018 was considered for inclusion and a narrative approach was adopted to critically appraise the texts. The literature review provides insights that enable the identified areas of strategic importance for carers to be empirically grounded, and that point to directions for future research.

Carer participation in employment and education

The literature recognises the need for policies, programs and services to support increasing numbers of citizens who, in light of demographic, socio-economic and service system factors, need to balance work and care responsibilities. Commentators also recognise that a focus on carer participation, especially for younger carers, benefits when a 'social inclusion' framework is used to develop a more comprehensive account of carers' lives and relationships. Social inclusion for carers would place a holistic focus on their participation in education and training, in community events and other civil society activities, and in employment. Integrated and coherent policy measures that cut across traditional government departmental boundaries would contribute to these outcomes.

Studies have investigated carers' decision-making around employment, strategies to support carers, carer-friendly workplaces, and employment support for carers. Longitudinal studies provide data that can continue to be analysed to track the employment of carers in an ever-changing labour market. Services helping young carers to transition through their educational milestones and into employment would benefit from evaluation.

Studies highlighting best practice employment assistance for carers, innovative strategies for supporting carers into education and training and the nature of carer-friendly workplaces can be drawn on to contribute to a deeper applied understanding.

Carer health and wellbeing

Carer health and wellbeing, and the services that contribute towards its promotion, is a key focus of practitioners, policy makers, researchers, academics, and carers themselves. The majority of the texts sourced and analysed in this review of the literature address this broad topic. The studies focus on, amongst others: the caring experience and carers' key concerns; initiatives, programs and services aiming to promote carer health and wellbeing; the effectiveness of professional interventions; the relationship-based helping process inherent to caring; and the links between carer health and wellbeing, carers' information about, and access to, services, and the engagement of carers as partners in care and decision-making.

The evidence is strong that multi-component or multi-dimensional interventions are more successful than isolated interventions in addressing the broad range of stressors that impact upon carers' health and wellbeing. Research evidence is growing for the effectiveness of specific interventions for specific groups of carers and also for interventions which target specific carer outcomes, such as reducing carer burden. Future research can build on this solid tradition of scholarship, while paying attention to the need for research designs that separate out different parts of multi-component interventions and then models their unique impact on identified outcomes.

In addition to a focus on interventions, research is required that addresses systemic and organisational issues, such as care coordination and partnership working. There are also recommendations in the literature for a stronger research focus on specific, often under-served, groups of carers, such as male carers and Aboriginal and Torres Strait Islander carers.

Access to information and community awareness

Carers' access to information is closely tied to their access to, and use of, the supports that will help them to address their health and wellbeing needs. People who have assumed care responsibilities need firstly to self-identify as 'carers' in order for them to be open to carer-related information. When they actively seek information, carers use a range of sources (including health professionals), modes (including online), and content, including care situations where carers experience uncertainty and could benefit from having more information or training. Systematic reviews suggest that there is on the whole a poorly developed and theorised concept of 'information needs of carers' in the papers focusing on the topic. It may help to begin with a classification into two broad areas: general information (for carers as a whole) and specific information (addressing the unique needs of each caring situation).

Information-provision may often be considered as part of a multi-component intervention, and isolating its specific effects can be difficult. There is a strong research interest in the role of the Internet as a source of information for carers, and also recognition that relying on it depends on the carer being able to critically appraise the information and process it within the context of their situation. There is a lack of research on the broader community's understanding and awareness of carers. More research is also needed that would help to fill identified gaps in understanding carers' information needs, especially in light of the impact of social media and the Internet more broadly, and the impact of information content and mode of delivery on specific carer outcomes.

Carer engagement

The literature points to the complementarity of informal and formal care in the modern world which necessitates collaboration – service providers need to engage and enter into partnerships with carers, both those that self-identify as carers as well as those that are 'hidden' carers. Carer engagement occurs at the level of individual caring situations and at the more systemic level of involving carers as key stakeholders in the policy and strategic planning processes. While carers can be sources of support in formal service provision, they can also be co-workers that work in partnership with service providers. When carers are in need of support services themselves, they may become co-clients. All of these factors contribute to the complexity of carer engagement and also to the research agenda.

Research suggests that engaging carers as partners in care and decision-making works best when professionals identify and welcome carer expertise, and when provider-carer partnerships include strong levels of collaboration from the start. Professionals can work with carers to develop the protocols and guidelines for partnership working, and the collaboration may also include carers and service users involved in the training of professional service users, carers' involvement in committees to plan and manage services, and regular discussion meetings outside of work environments between stakeholders.

Research that is more theoretically and professionally informed would generate insights – and provide evidence to improve – the effective and appropriate engagement of carers in models of consumer-directed care, such as the National Disability Insurance Scheme. Research could be directed at better understand practitioner-carer collaboration, and evaluating the programs and services, such as clinical case management, in which this occurs.

Evidence to shape policy and programs

A priority area in the *NSW Carers Strategy 2014-2019*, and a key focus for the Centre for Carers Research, is to develop strategies promoting the better use of available data and research to help shape policy and programs. While international and Australian research on carers is dynamic and extensive, it remains important to strive for higher quality evidence that is applicable to the real lived experience of carers and those they care for. Similarly, there is the need for greater understandings of caring contexts, processes, facilitators and barriers.

Recognising that carers are themselves consumers of information, more could be done to enhance the reach of research outputs so that they have a more explicit and practical impact on the lives of individual carers and the people they care for. Three broad strategies are discussed in this report:

- Operating a carer-specific online database
- Synthesis of the research evidence widely disseminated
- Trustworthy, signposted, user-friendly online information.

Insights from the literature on involving carers in research is also provided. This literature suggests that there is great value in actively including carers in evidence base and practice-oriented research; and that connecting with carers will require an in-depth understanding of how to use social media and other means of recruitment.

Issues of special significance for Aboriginal and Torres Strait Islander carers

Throughout the conduct of the literature review, an additional lens was applied to publications focusing on Aboriginal and Torres Strait Islander carers in order to address the research question: How can the evidence base to understand and support Aboriginal and Torres Strait Islander carers best be promoted? All of the current research on carers has significance for Aboriginal and Torres Strait Islander carers, but it should be complemented by research focusing specifically on these communities. In doing so, it can also draw on research conducted internationally amongst First Nations and Indigenous carers.

Research suggests that carers from these communities do not always recognise themselves as 'carers'. Instead, they view the caregiving that they carry out as an accepted part of their normal kinship roles. The available data points to poorer health outcomes and a higher burden of care among Indigenous carers relative to non-Indigenous carers. At the same time, high levels of the positive aspects of caregiving are frequently discerned in qualitative research. Factors common to supporting Indigenous carers in Australia, New Zealand and Canada, include: support for carers to identify as carers; access to culturally appropriate and timely information; culturally safe services; recognition by health and disability systems and broader society of the contributions of Indigenous carers; and communication and coordination among service providers, communities and caregivers. There is also benefit in striving for a deeper understanding of the diversity of carers and caring situations.

There is a need for high quality research on all aspects of caring in Aboriginal and Torres Strait Islander communities. While there is a clear role for qualitative research designs and methodologies, many current studies, according to conclusions in the current literature, contain numerous methodological weaknesses that compromise the reliability and validity of findings. Future research in this area would benefit from greater adherence to the standards of research that contribute to a strong and reliable evidence base.

Contents

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1 Introduction

1.1 Policy and institutional background

The Centre for Carers Research was established in 2018 with funding from the New South Wales (NSW) Department of Family and Community Services (FACS). It is located within the Institute of Public Policy and Governance at the University of Technology Sydney as a strategic research program dedicated to improving the evidence base for carers. The Centre works in close collaboration with carers' organisations, policy-makers and service providers and other researchers both in Australia and internationally. In particular, the Centre will work with FACS and the non-government sector to develop an annual program of industry-relevant research drawing on existing data and new primary data collection, analysis and dissemination.

Primary research will align with the priority areas of the *NSW Carers Strategy 2014-2019* (Department of Family and Community Services NSW, 2014) to ensure that it targets areas of strategic importance for carers. Priority areas outlined in the *NSW Carers Strategy 2014-2019* (the Strategy) together with their expected outcomes are:

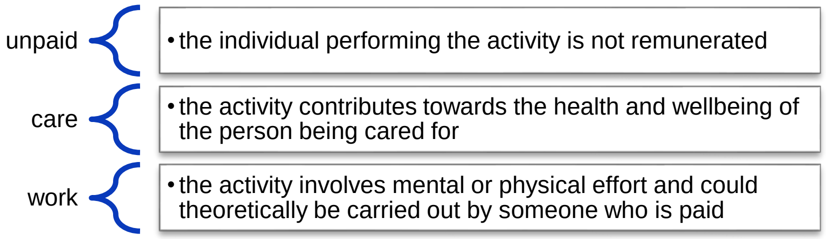
1. **Carer participation in employment and education** – carers have choices and opportunities to participate in paid work; young carers complete school and transition to further education and employment
2. **Carer health and wellbeing** – improved design, delivery and evaluation of services and programs in order to facilitate and promote carer health and wellbeing
3. **Information and community awareness** – carers are able to easily access information when they need it; carers feel that the broader community understands their experience
4. **Carer engagement** – service providers work with carers and include them in the decisions and practicalities that affect themselves and the people they care for; policy makers and providers involve carers in decision-making on the design and delivery of services, especially at the local level
5. **Evidence base** – policy and practice is informed by quality evidence and better use is made of available data.

The Centre for Carers Research has been funded for an initial three years to contribute in a major way towards achieving the latter outcome, which interlinks comprehensively with outcomes in the four other priority areas.

1.2 Caring and carers: basic understandings

In Australia and internationally, a far-reaching policy shift in recent decades contributed to a decline in institutional care models and towards providing care for those who need it in the community, preferably within their own homes. Caregiving provided most often, but not exclusively, by family members, became the critical element to this policy shift, with the result that the provision of unpaid and informal care in the community is nowadays an important foundation for a wide range of social policies (Bittman, Hill and Thomson 2007: 256).

The Australian Bureau of Statistics Survey of Disability, Ageing and Carers identified 2.7 million carers in 2012 (around 12 per cent of the population). Of these, 770,000 were primary carers, that is, people who provide the most assistance to a person with a core activity need for assistance (Hill, Thomson, Raven et al. 2016: 138). As of 2018, there were an estimated 2,700,800 carers in Australia (Commonwealth of Australia 2018: 9). Carers 'provide ongoing unpaid support to people who need it because of their disability, chronic illness, mental ill-health, dementia or frail age' (NSW Government 2014: 4). Other definitions highlight the fact that the support is 'provided in the context of familial or other prior affective relationships' (Yeandle, Yeah-Ching, Fine et al. 2017: 10). Ferrant, Pesando and Nowacka (2014) identify three variables of informal caring through defining 'unpaid care work' as follows:



unpaid	• the individual performing the activity is not remunerated
care	• the activity contributes towards the health and wellbeing of the person being cared for
work	• the activity involves mental or physical effort and could theoretically be carried out by someone who is paid

Figure 1: What is 'unpaid care work'?

Building on the classification developed by Vassilev et al. (cited in Knowles et al. 2016), caring comprises three domains of work:

- **Disability, illness and frailty-specific work** – tasks related to treatment regimes, managing symptoms and engaging with formal healthcare providers
- **Everyday work** – household tasks, care of the wider family, aspects of managing general health including diet and exercise, and personal care
- **Emotional work** – diffusing worry and anxiety, and managing aspects such as personal identity, plans for the future, expectations and relationships.

Carers SA (2017: 5) points out that 'carers come from all walks of life, all cultures and all religions. Some are children while other are nearing 90…Every care situation is different'. Understanding these variations is important for all serious scholarship focusing on carers and caring. For example, the Informal Care Model was put forward by Brouse van Groenou and de Boer (2016: 272) on the basis of a synthesis of theoretical and empirical understandings of informal caring. It is a behavioural model that enables consideration of the wide diversity among carers and caring situations. The Model has three central propositions:

I. Informal caregiving starts with the notion that someone in the social network is in need of care.
II. Individual dispositional factors predict to what degree one intends to provide care.
III. Whether one will actually provide care depends on external conditions that facilitate or restrict the provision of care.

The model also draws attention to the interdependence of caregiving among four levels, namely the caregiver – care receiver dyad; the family; the social network; and the community-based and private service sectors. The researchers suggest that the Model 'may be applied in empirical studies to explain individual variety in informal care provision…it may also be applied to answer more complex research questions involving longitudinal, multi-actor or cross-national designs' (Brouse van Groenou and de Boer 2016: 275).

According to ACIL Allen Consulting (2014), several factors contribute to increasing the importance of, and demand for, carers in Australia:

- The increasing proportion of the population that is ageing
- Community preferences
- Policy and practice that encourages and supports people with caring needs to remain in their homes for as long as possible
- The intention of specific policy reforms, such as the National Disability Insurance Scheme (NDIS) and *Living Longer Living Better* aged care reforms.

1.3 This report

1.3.1 Objective and research questions

This literature review was carried out in order to gain an understanding of current research and debates relevant to the five focus areas of the *NSW Carers Strategy 2014-2019*, and of directions for future research. Research questions were put forward for each of the five focus areas in order to guide the review of current literature:

Employment and education:

- What are the issues and debates regarding carers' participation in education and employment?
- What is the research evidence for services and programs that aim to assist carers to participate in paid work and education?
- Where could research be directed in terms of the employment and education of carers?

Carer health and wellbeing:

- What are the current issues and debates regarding the promotion of carer health and wellbeing?
- What is the research evidence for services and programs that aim to assist carers to look after their own health and wellbeing?
- Where could research be directed in terms of carer health and wellbeing?

Information and community awareness:

- What are the issues and debates regarding information for carers and community awareness?
- What is the research evidence for services and programs that aim to ensure that carers are able to easily access information when they need it and for raising community awareness of the carer experience?
- Where could research be directed in terms of enhancing carers' access to information and raising community awareness about the carer experience?

Carer engagement:

- What are the issues and debates regarding engaging carers as partners in care and decision making?
- What is the research evidence for services and programs that aim to promote carer engagement?
- Where could research be directed in terms of carer engagement?

Evidence base:

- How can better use be made of available data and research to create evidence to shape policy and programs that are of benefit to carers?
- How can the evidence base to understand and support Aboriginal and Torres Strait Islander carers best be promoted?

1.3.2 Methodology for the literature review

The conduct of this study was guided by the understanding that a literature review is a 'secondary analysis' research method that seeks, presents, and analyses 'formal knowledge that has been articulated, codified and stored in an accessible format' (Jesson, Matheson and Lacey 2011: 16). It makes use of that analysis to generate new insights, particularly – in consideration of the research questions for this study – insights that contribute to applied policy and practice.

The focus was on peer-reviewed journal articles, research reports, carers' resources and other practice, policy and theoretical texts published in English from 2008 to 2018. The electronic databases consulted included, but were not limited to, Academic Search Complete (EBSCO), Google Scholar, INFORMIT, Ovid MEDLINE, ProQuest, SAGE Journals Online, Taylor and Francis Online, and Wiley Online Library.

In addition, the search for literature drew on specialised carer databases including the 'Research Snapshots' collection maintained by CarersNSW, the Carer Research and Knowledge Exchange Network (CAREN), and Caresearch Palliative Care Knowledge Network.

The search terms were drawn from the study's research questions, described above, and include, but were not limited to care/caregivers/caring + informal/unpaid/family + employment and education + health and wellbeing/promotion/services + information/community awareness + engagement/participation + Aboriginal and Torres Strait Islander + research/evaluation/evidence.

1.3.3 Presentation and analysis

A narrative approach was adopted to critically appraise the material (Rhoades 2011), with an emphasis on generating insights that could inform the above-outlined areas of strategic importance for carers. The report's underlying structure conforms to those five priority areas. A synthesis is provided in the final chapter. Except for priority area 5 (Evidence base), each Chapter contains:

- ➢ a brief discussion of issues and debates pertaining to the topic
- ➢ presentation and analysis of the research; in each Chapter, empirical studies related to the topic – particularly those that are themselves literature reviews –are summarised in a 'table of evidence' (Reychetnik and Frommer 2002) and drawn upon to generate evidence of the effectiveness of interventions, or empirically sound descriptions of good practice, and of gaps in the literature
- ➢ directions for future research.

The final chapter draws on analysis of all the studies included in the literature review, including the texts highlighted in the tables of evidence, to provide an empirically informed synthesis and response to the research questions.

2 Employment and education

2.1 Issues and debates

Several factors have impacted on employment in the 21st century that are of relevance to the participation of informal carers in the labour market. Globalisation is one of them. As described by Fine (2012: 60), a consequence of globalisation is that ‘employment is becoming internationally competitive and intensified, with work hours extending and great demands being made on employees ... at the same time there are increasing calls to extend the working life by raising, indeed in many cases abolishing, the age of retirement’. When taken together with demographic changes (Ireson, Sethi and Williams 2018), the consequence is that increasing numbers of people need to balance work and informal caring responsibilities. Impactful demographic changes include (Yeandle et al. 2017):

- increasing longevity, with larger proportions of the population aged 75 years and older
- lower fertility rates
- increased female labour force participation
- the greater mobility of populations.

Issues of combining caring duties with education and employment, and coping, are important to young carers (younger than 25 years) for whom schooling milestones and their moves into higher education or employment are key life transitions. These issues have increasingly become major concerns for carers older than 25 and for all employees who find themselves needing to take on informal caring responsibilities.

Approaches to improving employment opportunities for carers would benefit from not viewing paid employment and informal care in dichotomous terms (Fine 2012: 64-67). This suggests placing a focus upon care and carer friendly workplaces that have provisions for care leave, paid and unpaid leave and flexible work patterns; increased access to services; cash for care schemes as payment of family carers; and the innovative use of technology.

Taking a broader approach, Hill, Thomson, Raven et al. (2016) have suggested that application of the concept of ‘social inclusion’ can assist in developing a more comprehensive account of carers’ lives and relationships. While engaging in education and employment are important, carers have a crucial part in the health and social care system. Social inclusion for carers would thus incorporate a focus on self-identity as a carer as well as recognition of this by families, communities and workplaces, which would then be reflected in policy and service provision. This will enable carers to have opportunities for choice in taking on the care role, and participation in education and training, in community events and other activities, as well as in employment (Hill et al. 2016).

2.2 Evidence

The key texts relating to carers’ employment and education are analysed in a ‘table of evidence’ (Table 2 in this report). Papers are included in the table of evidence if they describe research studies that generate findings on services and programs that aim to assist carers to participate in paid work and education, including evaluations of the effectiveness of interventions to support carers’ employment and education. Drawing in particular on these studies, key findings from this analysis of the empirical literature are discussed next.

2.2.1 Supporting young carers through key transitions

Young carers can be described as ‘children and young people aged 25 or younger who provide substantial unpaid support to a family member with a chronic illness, disability, mental health issue and/or problems with alcohol or other drugs’ (Hamilton and Adamson, 2013: 101). Hollingworth (2012: 442) writes that a focus on ‘education in its broadest sense’ is helpful when addressing the effective and appropriate integration of care and education, especially for young carers. This suggests that activities such as participating in sport, volunteering, artistic and cultural activities, and socialising with friends all contribute to helping young people who dedicate time to providing care to family members to more easily integrate into their broader social environment, which also helps them integrate into the world of work.

While it is essential, therefore, to support young carers to complete their schooling, and move into higher education or employment, there is value to consider this as part of provision of a broader range of supports for young carers through key transitions (Carers SA 2017). A holistic, developmental perspective for young carers is presented in Table 1 below.

Table 1: Transitions for young carers

LIFE STAGE	EXPERIENCE OF YOUNG CARERS	TRANSITION EVENTS AND NEEDS	SERVICE STRATEGY
MIDDLE CHILDHOOD: 5 – 8 YEARS	'keep an eye out' listener and supporter provide company basic support tasks	Starting primary school The usual excitements and apprehensions may be exacerbated	Review the transition to school with the young carer and family Resource that visually lists core contacts for the young carer at school
LATE CHILDHOOD: 9-13 YEARS	take on more responsibilities at home; most will have added to the tasks performed in earlier years assist with general household cleaning chores, food preparation, personal care and other tasks	End of primary school Reflecting and planning for high school	Help child to consider achievements and growth Provide a visual overview of existing support networks Watch for feelings of inadequacy and inferiority when comparing to peers
ADOLESCENCE: 14-17 YEARS	often start taking on the responsibilities of an adult carer may display advanced maturity	Starting secondary school Ending secondary school	Support in juggling a new education environment with increased responsibilities in the caring role Flexible learning, tutoring and other means to support educational outcomes Career counselling Wellness and resilience development training
YOUNG ADULT: 18-25 YEARS	often take on full management of the household can be isolated from peers	Stepping into the adult world Perhaps opt to become a full-time family carer Perhaps transition to higher education	Investigate support for carers at universities and colleges and encourage to access student advisory services Explore apprenticeships and traineeships, and employment options Focus on significant relationship shifts from core family to partners and friends

Source: drawn from CarersSA (2017: 11-28)

As can be seen in the table above, a sensitivity to transitions in young carers' lives can assist providers in planning and resourcing their service strategy. Also useful is the concept of 'bounded agency', explored and developed by Hamilton and Adamson (2013) through research carried out in Australia. It helps in a more comprehensive understanding of the way in which young carers make decisions and develop aspirations. Bounded agency explores

> *…the way in which structural factors in their past and present shape their daily experience across major life domains, their sense of future possibility and the way that their decisions and plans may be socially and temporally situated. The emphasis is on the way in which young carers exercise agency and experience constraints across different life domains such as participation in education and employment and in the development of their social relationships and health and well-being.*
>
> (Hamilton and Adamson 2013: 103)

Services should be designed to limit the extent to which caring responsibilities place constraints on the actions of young carers in their daily lives; and to reduce the bounded – and hence limited – sense of possibility that young carers often express (Hamilton and Adamson 2013: 115).

2.2.2 Factors impacting on carers' participation in paid work

Factors relating to each particular caring situation, to carers' life circumstances and to the labour market and workplace characteristics all have an impact on carers' decision-making around paid work. Factors identified by Arksey and Glendinning (2008) include carers' financial needs, conditions pertaining to carer support payments and the provision of formal care services, such as home help, and practical issues such as distance, transport and travelling time. Research carried out by Pickard et al. (2015) in the United Kingdom (UK) provides support for the contention, made by several other commentators, that carers and more likely to be employed when they can draw on formal services to provide some of the caregiving. Put differently, carers are more likely to look for and find work when the people they care for are receiving services from formal providers.

Carmichael et al. (2008) provide strong evidence that carers who care for longer hours and longer durations are more likely to change their hours of work or their jobs, or leave employment completely, after becoming carers. Through analysis of Household Income and Labour Dynamics Australia (HILDA) data, Hill et al. (2008) discovered that being in casual employment, working part-time prior to caring, having no supervisory responsibilities, not belonging to a union, working for a smaller firm (less than 100 employees) and few carer-friendly workplace arrangements were all associated with a higher risk of carers leaving employment. In contrast, access to at least one workplace arrangement – special leave for caring, permanent part-time work (especially for first-time carers), flexible start and finish times, or home-based work – promotes remaining in employment.

2.2.3 Strategies to support carers into employment

From a social policy point of view, there is support in the literature for carers' issues to be integrated and consolidated into coherent policy measures that cut across traditional government departmental boundaries. These include policies related to employment and workplace relations, social security benefits, health, social services, transport and housing (Arksey and Glendinning 2008). As discussed by Carmichael et al. (2008), the network of providers to help people combine work with their caring responsibilities would include, at a minimum, employment support, the health and social care systems, and the social security system.

The promotion, development and support of carer-friendly workplaces is an important strategy for supporting carers. Carers NSW (2016: 11) has suggested that the culture of the workplace and the carer's perception of having a supportive employer are especially important in being able to combine unpaid caring duties with paid work. On the basis of an analysis of carer-friendly workplaces throughout the world, Ireson, Sethi and Williams (2018) identified four common themes:

diversity and inclusiveness

- workplaces have a definition of 'caregiving-employees'; they recognise their diverse workforce; they break down restrictive norms around care-giving

employer motivation

- workplaces highlight the business case of employing carers; they recognise the demographic challenges that will impact upon their and all other workforces in developed countries; they promote corporate social responsibility

accessibility

- employers address the potential stigma associated with managing a carer-friendly place of work; they view case-by-case solutions as the most effective

workplace culture

- carer-friendly workplaces that are driven by core business values and workplace characteristics supportive of carers' needs

Figure 2: Elements of carer-friendly workplaces

Source: based on Ireson et al. (2018)

2.2.4 Employment assistance for carers

A suggested model for employment support for carers is provided in Box 1 below, drawing on research carried out in 2014 by the National Institute for Health Research (NIHR) in Leeds UK.

Box 1: Good practice employment assistance for carers

Employment support should be incorporated into a package of tailored assistance that addresses the diversity and complexity of carers' needs. This requires successful partnerships, often informal, that facilitate collaboration between the employment service and other services in the health and social sectors, such as GPs, hospitals, pharmacies, colleges and training providers.

The most effective aspect of employment support is flexible provision of training courses to build and develop carers' skills and confidence for the world of work. Carers should be able to access this training alongside their caring commitments.

Employment support staff are needed with qualifications and experience to support carers with complex needs. Their skills include:

- **understanding carers' issues**
- **experience of dealing with a diverse range of people**
- **patience**
- **the ability to deal with emotional issues**
- **maintaining an objective distance from problems.**

In order to ensure that carers are aware of the specialised employment supports available in their areas, attention should be paid to proactive marketing.

Source: drawn from NIHR (2014)

In terms of both the practical and confidence-building aspects of employment support, providers should acknowledge the attributes and competencies that carers already have and, indeed, that they have honed through their caring work. ACIL Allen Consulting (2014) found that the transferable skills and knowledge that carers develop through their caring work include **time management**, **financial skills**, **adaptive problem solving**, **health care skills**, and **advocacy skills**. Strategies identified in the literature (ACIL Allen Consulting 2014) to support carers into employment and education include:

- Mentoring programs, foundation skills support and courses leading to qualifications
- Carer-sensitive recognition of prior learning (RPL)
- Supporting effective transitions at the end of secondary school
- Training subsidies, incentives and study allowances
- Flexible delivery options for tertiary education and training courses
- Training courses designed specifically for carers
- Integrated support practices that also address other psychosocial needs of the carer
- Carer Passports.

One of the strategies identified above is use of a Carer Passport, described in greater detail in Box 2.

Box 2: Carer Passports

The Carer's Passport provides a common framework for staff and carers and puts a value on the contribution made by carers in caring for the person who is ill or disabled. It recognises the positive difference that carers make to the experience of a person while they are in hospital or nursing home care. The Carer's Passport acts as an access card which allows a named carer to visit their relative at any time. It is pre-signed by a senior member of staff and publicised through posters outside the ward area, thus encouraging carers to approach staff and ask for one. The passport does not contain any information about the carer or the patient, but the fact of a carer having one encourages staff to ask carers whether or how they would like to be involved. This means that care can be planned to take a carer's preferences into account.

Source: based on Bray and Evans (2015)

In acknowledging this societal role, the Carer Passport contributes an attribute to the carer's wider range of attributes and competencies that a wide range of employers will find attractive.

The table of evidence for texts focusing on the 'employment and education' theme, and from which many of the observations discussed above derive, is presented below.

Table 2: Table of evidence: Supporting carers' participation in employment and education

Authors	Study aims and methods	Key findings	Implications
Ireson, Sethi and Williams (2018)	Scoping review focusing on carer-friendly workplace policies from around the world. All studies published from 1994 to 2014 were included; 70 articles met the inclusion criteria, of which only 2.8% were peer-reviewed academic articles. The studies were qualitatively analysed in order to generate the characteristics of 'caregiver-friendly workplace policies' (CFWPs).	Four main themes were identified: • **Diversity and Inclusiveness** – this includes defining 'caregiving-employees'; recognising the diversity of employees; and breaking down norms around care-giving. • **Motivation** – highlighting the business case of employing carers; recognising the demographic challenges; corporate social responsibility • **Accessibility** – including the stigma associated with CFWPs and the view that case-by-case solutions were the best • **Workplace Culture** – driven by core business values and workplace characteristics.	There is value in identifying carers in the workplace and recognising their needs. Managers would benefit from training to recognise and support carers. Workplace cultures should reflect the diversity of employees, including carers. Workplace flexibility is desirable, but ideally carers themselves should be able to choose the strategies that best help them to combine work with caring. Campaigns could be directed at addressing stigma related to caregiving.
Hill, Thomson, Raven et al. (2016) **Carers and Social Inclusion Project (UNSW)**	The project, funded through a Australian Research council grant, had four aims: • to document carers' social exclusion • to reconceptualise social inclusion • to provide evidence to inform policies • to develop indicators of social inclusion most relevant to Aboriginal and Torres Strait Islander carers	Key findings relating to carers' participation in employment and education included: • Carers were less likely than non-carers to participate in employment and had lower secondary education achievement. This effect was enhanced for female carers. • Location has an effect on the achievement of social inclusion outcomes. • The quality of participation is as important as the quantity. A focus on quality includes relationships, the caring situation (e.g. access to information and training); employment satisfaction, and the ability to balance multiple responsibilities.	The concept of social inclusion needs to be revised on the basis of a more comprehensive account of carers' lives and relationships. While engaging in education and employment are important, all levels of society would recognise and respect the important role carers have in the health and social care system. Social inclusion for carers would thus incorporate: • self-identity as a carer • family recognition • community and workplace recognition • policy and service providers' recognition.

Authors	Study aims and methods	Key findings	Implications
Pickard et al. (2015)	The study examined the effectiveness of paid services for the cared-for person in supporting unpaid carers' employment. The researchers drew upon data from the 2009/10 Personal Social Services Survey of Adult Carers in England. The survey includes questions on both the employment of the carer and the services received by the cared-for person. An eligible population of 175,600 carers was identified and 87,800 were randomly selected and sent a postal questionnaire. A total of 35,165 carers then responded (40% response rate).	The existing international literature on the effectiveness of paid services as a means of supporting unpaid carers in employment is inconclusive. Where the cared-for person receives at least one paid service, women and men providing unpaid care for ten or more hours a week are more likely to be in employment than if the cared-for person does not receive any services. Other factors that are positively associated with carers' employment include good health on the part of carers and providing fewer hours of care, as well as, for women carers, being in mid-life or older.	gives support to the hypothesis that services for the cared-for person are effective in supporting carers' employment
ACIL Allen Consulting (2014) **Study undertaken on behalf of the Community Services and Health Industry Skills Council and Australian Government Department of Social Services**	A review of the literature was carried out The aim of the review was to examine: • the skills and knowledge that carers develop through their caring work and their transferability to paid employment • approaches that support carers' transition into	Transferable skills and knowledge that carers develop through their caring work include: • time management • financial skills • adaptive problem solving • health care skills • advocacy skills. Strategies identified in the literature to support carers into employment and education include: • carer 'passports' and mentoring programs • foundation skills support and courses	There is a lack of high quality research available in relation to informal carers, their skills and knowledge, education and training, or on their transition to employment. Only a small amount of this research has been undertaken in Australia. Further research is needed to explore how best to highlight the promotion of transferable skills into paid employment.

Authors	Study aims and methods	Key findings	Implications
	education, training and employment - the role of, and approaches to, supporting carers' engagement in education and training	- recognition of prior learning (RPL) opportunities - supporting effective transition from secondary education - training subsidies, incentives and study allowances - flexible delivery options for tertiary education and training courses - training courses designed specifically for carers - integrated support practices.	
NIHR (2014)	Case study, including a survey of 86 service users, of voluntary sector organisations that have a track record of providing innovative employment support for carers. A 'hard' outcome was defined as achieving the following as a result of accessing the support services: - Stay in work - Start paid work - Start work as self-employed - Progress into training or further education.	Four core features of effective employment support: - Flexible provision of training courses, which carers could access alongside their caring commitments - Tailored support to cater for the diversity of carer needs, of which employment support could be just one. - Staff with the right set of skills based on qualifications and experience of supporting carers with complex needs. Skills include understanding carers' issues, experience of dealing with a diverse range of people, patience, the ability to deal with emotional issues, and maintaining objective distance from problems. - Successful partnerships, often informal, that enabled the employment support service to work well with GPs, hospitals, pharmacies, colleges and training providers. Lack of funding presented a key challenge. Linked to this, the ability to resource proactive marketing was also a common challenge. This led to low awareness among carers of the availability of specialist employment support.	Effective employment support for carers is most effective when characterised by flexible skills provision, which carers can access alongside their caring commitments; and tailored support to meet the diversity and complexity of carers' needs. The good practice of employment support organisations is rarely taken up, evaluated and implemented more widely, often due to the short-term and unreliable nature of funding. Policy makers could encourage a partnership approach to the funding of employment support services – joint partnership working between the public, private and voluntary sectors.

Authors	Study aims and methods	Key findings	Implications
Hill et al. (2008) **Bittman, Hill and Thomson (2007)**	The researchers analysed data from the longitudinal Household, Income and Labour Dynamics in Australia (HILDA) survey: - to examine the effect of caring on employment, hours worked and earnings - to discover characteristics of employment that might reduce the likelihood of workers leaving work once they become carers.	Informal carers struggle to reconcile the demands of the labour market and the time needed for informal caring, with the result that many substitute unpaid work for paid work. A significant loss of income results when a family member takes on caregiving duties, and this effect may continue over many years, perhaps over the carer's lifetime. Being cared for at home is a clear preference of most care recipients, but a consequence of this is that the cost of caring has shifted largely to private households, and, within these households, predominantly to women. Working-age informal carers are more likely than the rest of the population to reduce their hours of work or withdraw from the labour force altogether. The nature of specific types of work and employment conditions in those jobs influence carers' decisions to remain or not in employment. These include the ability to use permanent part-time work in the current job (most significant); home-based work; flexible start and finish times; and carer's leave arrangements.	Informal caring is prevalent enough to be picked up in moderately sized surveys of Australian households. While there is a substantial literature on combining work with the care of healthy young children, the literature on carers of adults or children with a disability is relatively sparse. Further research is needed to determine whether there is an asymmetrical relationship between caring and hours of employment, that is, where hours of employment and levels of earning never return to the levels of the pre-caring situation. This would have clear policy implications. The design and use of data from longitudinal studies (such as HILDA) should be encouraged in order to generate reliable and usable data.
Carmichael et al. (2008)	This study carried out in the UK examined the impact that caregiving responsibilities have on carers' employment. Research methods included a questionnaire survey (N=272) and semi-structured interviews with 26 carers.	Carers who cared for longer hours and longer durations were more likely to change their hours of work or their jobs, or leave employment completely, after becoming carers. As a caring episode continues, some carers also change their jobs in order to continue combining paid work and care (presumably because they find that the hours in their current jobs are not sufficiently flexible). Other carers give up paid work altogether. Support from employers and the formal care services, as well as financial help, are clearly important for carers, both for those who wish to combine caring and employment, and for those who do not. Many carers also	Many carers would like to, or have the need to, combine paid work with the informal care they provide, and policies should enable this. Informal carers continue to face difficulties when they try to combine employment and care in spite of the policy initiatives in the UK that were designed to help them. The network of providers that help people to combine work with caring responsibilities includes the care systems, employment support and social security.

Authors	Study aims and methods	Key findings	Implications
		need specialist employment support when returning to employment after a long period of caregiving.	
Arksey and Glendinning (2008)	A large-scale qualitative study was carried out in the UK. In-depth interviews were conducted with carers (N=80) who had caring responsibilities of 20 or more hours per week. The objective was to examine carers' decision-making around combining work and care.	Factors affecting carers' decision-making around combining work with their caregiving duties included: • The need to earn money • Conditions pertaining to carer support payments • Work-related factors, including especially perceived and actual local job opportunities, and the extent to which particular jobs offered workplace flexibility • Provision of formal care services, such as home help • Distance, transport and travelling time. There is evidence that carers consider trade-offs between the stresses associated with employment and the role that work has in maintaining, and even enhancing, their socio-emotional wellbeing.	The future supply of informal carers is likely to depend to a greater extent on people being able to combine caring and work. Policies need to be designed in light of this trend. Carers' issues should ideally be integrated and consolidated into coherent policy measures that cut across traditional government departmental boundaries. These include policies related to: • employment and workplace relations • social security benefits • health • social services • transport and housing.

2.3 Directions for future research

ACIL Allen Consulting (2014) write that there is a lack of high quality research available in relation to informal carers' skills and knowledge, education and training, or on their transition to employment. In particular, these researchers note that only a small amount of this research has been undertaken in Australia. Nonetheless, this literature review suggests that the evidence base is growing. Australian researchers are well placed to contribute to this evidence base.

Directions for future research include evaluation of services that provide, amongst others:

- Flexible learning, tutoring and other means to support educational outcomes
- Career counselling
- Wellness and resilience development training
- Support for carers at universities and colleges and encourage to access student advisory services
- Apprenticeships and traineeships
- Innovative employment options

Based on the research carried out by Arksey and Glendinning (2008), research needs to ground itself and ideally take empirical account of the impact of policies. The complex context includes policies related to employment and workplace relations, social security benefits, health, social services, transport and housing.

The work of researchers at UNSW (Hill et al. 2008; Bittman, Hill and Thomson 2007) points to the value of adopting a longitudinal approach to studying carers and their engagement in paid work. The researchers analysed data from the longitudinal HILDA survey and showed that informal caring is prevalent enough to be picked up in moderately sized surveys of Australian households. Amongst others, the researchers recommended that further research is needed to determine whether hours of employment and levels of earning ever return to the levels of the pre-caring situation. This would have clear policy implications.

In terms of employment support, the good practice of employment support organisations is rarely taken up, evaluated and implemented more widely, often due to the short-term and unreliable nature of their funding (NIHR 2014). Policy makers could encourage a partnership approach to the funding of employment services, suggesting joint partnership working between the public, private and voluntary sectors. Greater stability would also provide stronger opportunities to incorporate a solid research agenda on employment assistance for carers.

3 Carer health and wellbeing

3.1 Issues and debates

3.1.1 Key concerns

In a report on a research study (the Australian Unity Wellbeing Index Survey) carried out in the early 2000s (N=4,107 carers), Cummins, Hughes et al (2007) declared that carers have ‘the lowest collective wellbeing of any group we have yet discovered…[although]…the wellbeing gap between the general population and the carers narrows with age’. In a more nuanced analysis of the data, the researchers also found that:

- The wellbeing of carers living with the person being cared for – generally the primary carers – is the lowest of all.
- Female carers have on average lower levels of wellbeing than male carers.
- Caring for an adult is less stressful than caring for children, but caring for one’s adult child imposes a heavier burden than caring for one’s spouse.
- There is no evidence that the burden of caring becomes systematically less over time.

These Australian data are in keeping with findings from around the world that informal caregiving impacts on the health and wellbeing of the carer. Focusing on carers of family members with disability in Australia in the context of the Families Caring for a Person with a Disability Study (FCPDS), Edwards et al (2008) discovered, amongst others:

- higher rates of mental health problems as well as poorer physical health compared to the general population
- difficulties engaging in the labour market
- financial hardship
- stresses associated with having multiple care responsibilities.

Carers raising children (with and without a disability) or those caring for multiple family members with a disability were at particular risk of worse mental health outcomes. In addition, the study found that around one in five carers had no support; and that those that did receive support often had disagreements about caring and problems of cooperating with formal services (Edwards et al. 2008).

Since 2002, Carers NSW has undertaken periodic surveys of carers across NSW, which, taken together with the ground-breaking ‘Dedication’ survey carried out in 1976, provide a longitudinal snapshot of key issues affecting carers over 40 years (Carers NSW 2016). The themes that are highlighted through this body of research include services and support issues. Consistent over several of the surveys is the finding that more than a quarter of carers do not access any formal services. The 2014 survey, for example, showed that the main barriers to carers accessing services were cost, not knowing what was available, and the priority they placed on their caring responsibilities.

An issue that is important for carer health and wellbeing is that caring takes place within the context of a relationship. Researchers that adopt psychotherapeutic approaches to supporting carers focus on the dynamic interplay between care-giving and care-receiving and the intense interpersonal relationships that these encompass (Bondi, 2008: 262). The underlying assumption is that the provision and the receiving of care is bound up within a relationship that incorporates the vulnerabilities of those involved, power dynamics, and the connections forged in and through the interplay of power and vulnerability. In light of this, psychotherapeutic approaches recognise that the quality of care relationships is not dependent solely or even primarily upon the ability of the carer to deploy expert knowledge about care needs: the relationship itself is also vital because ‘it is through this that needs and feedback about care are communicated.’ (Bondi, 2008: 262).

An aspect of the caring experience receiving research attention is the health and wellbeing of carers once their caring role comes to an end. Granaheim, Johansson and Lindgren (2014) investigated the experiences of carers of people with dementia once they relinquished care to a nursing home, and found that the period after relinquishing care was characterised by contradictory feelings: grief and loss, mixed with feelings of relief that the family member was safe. Many also noted their increased freedom. Adaption to the new situation can be facilitated if the family carers are recognised as partners in care, including regular meetings with staff; and by offering staff clinical supervision to deal with the emotional strain of carers (Granaheim et al. 2014.

3.1.2 Promoting carer health and wellbeing

A key task for researchers and practitioners focusing upon carer health and wellbeing is to develop greater understandings of the carer experience itself. Included in this literature review are studies by Hokanson et al (2018) and Hill et al. (2012) on better understanding the experiences and support needs of Aboriginal and Torres Strait Island carers; Lashewicz, Shipton and Lien (2017) focusing on fathers of children on the Autism Spectrum Disorder (ASD); and large cohort studies such as the Lifelines Informal Care Add-on Study (Lifelines ICAS) in the Netherlands (Oldenkamp et al 2017), which provide population level data on differences among carers, care recipients, and care situations, as well as the study of common characteristics and features across caregiver groups.

Hamilton and Cass (2017) argue for the importance of adopting a life-course perspective to understanding caring. A framework that takes account of the importance of age and life-course stage in shaping caring experiences and responsibilities draws attention to 'the way that life-course stage affects each aspect of the caring process and the way that care provision shapes the nature and extent of carers' participation in socially sanctioned, normatively structured stages, transitions and timetables' (Hamilton and Cass 2017: 90). This framework can provide a stronger basis on which to approach policy to support carers and the people for whom they care through its focus on the 'ethic of care'. Support for adopting a life course perceptive on caring additionally comes from the findings of longitudinal studies which show that, over the course of a working life, around one in two of all employees are likely to acquire substantial caring responsibilities at some time (Hill et al. 2008: 31).

A wide range of interventions to support carer health and wellbeing is discussed in the literature. An systematic review carried out by Arksey O'Malley, Baldwin et al. (2002) found that studies were investigating the effectiveness of a wide range of interventions, including counselling, the provision of home care services, home modifications (alterations to the physical environment), telephone and computer-based services, and structured breaks from caring i.e. the provision of respite care.

Educational interventions address the mastery and preparedness of the person providing informal care through, for example, the provision of skills to successfully and safely carry out personal care tasks. Amongst specific caring groups, such as carers of people with mental illness or dementia, psychoeducational interventions (see e.g. Parker, Mills and Abbey 2008) are a subset of educational interventions.

Psychosocial interventions address the holistic functioning of the carer within her or his environment, and generally have outcomes related to improved coping, better relationships, and enhanced problem-solving. They include family-focused interventions, such as family counselling; group work – mutual support and social activity groups; and self-care strategies focusing on 'issues of self-esteem, insight into an adaption to illness and its consequences, communication, social functioning and relationships' (National Council for Hospice and Specialist Palliative Care Services, cited in Hudson et al., 2010: 1).

Worrall et al (2018) write that carer support groups aim:

- to provide education and information in order to increase knowledge and understanding
- to encourage an atmosphere of mutual trust in which to explore strategies for coping
- to provide emotional support conducive to an open and honest sharing of feelings.

Multi-dimensional approaches offer a combination of services addressing a range of stressors in the carer's life.

3.1.3 Service information and access

Ensuring that carers have information about, and thus access to, services points to an aspect of carer health and wellbeing strongly linked to 'carer information', a priority area which is dealt with in greater detail in Chapter 4 of this report. Many authors do not make strict conceptual distinctions between carers' access to services and their use of those services, since both contribute to carer-focused outcomes. This should be born in mind when considering the literature. For example, in an 'evidence check' on best practice in caring for carers, Strobel and Adams (2015) point to the need for interventions that improve a carer's access to services, including whether there is adequate provision of services, what services are being used and how others can be improved.

3.2 Evidence

Research on the effectiveness of interventions is essential to enable professionals to operate with a suitable evidence base to support family carers (Hudson, Remedios and Thomas 2010). Effective interventions produce 'a significant improvement in caregiver burden, depression, subjective wellbeing, satisfaction, caring ability/knowledge and care' (Sörensen et al., cited in Williams and Adams 2009: 39). Studies that provide evidence are summarised in this chapter's table of evidence (Table 3). In light of the substantial literature available, preference was given to studies that are themselves systematic reviews and/or meta-analyses – of the five priority areas of the *NSW Carers Strategy*, this is the one that yields by far the most systematic reviews and meta-analyses of published research, which are indications of a strong research interest.

A feature of the literature on this theme is its specificity. Studies address the efficacy of specific interventions (such as counselling or case management) as well as specific caring situations (such as caring for people with intellectual disability or caring for people with severe mental health problems). At is most advanced level, research examines the effectiveness of specific interventions on specific outcomes for specific groups of carers. Hopkinson et al. (2018), who carried out a systematic review and meta-analysis of studies examining the effectiveness of cognitive behavioural therapy (CBT) to reduce stress and anxiety in carers of people with dementia, provides an example of this specificity.

Key findings from this rich body of literature are discussed next.

3.2.1 Multi-component interventions

A strong finding from the literature (see e.g. Abrahams et al. 2018; Strobel and Adams 2015; Williams and Owen 2009) is that multi-component or multi-dimensional interventions are more successful than single interventions at addressing carers' health and wellbeing needs. Abrahams et al. (2018), for example, suggest on the basis of a systematic review of the literature, that a combination of counselling, support groups, education, stress and mood management, and telephone support are important strategies within an effective multi-component intervention for carers of people with dementia. Also focusing on carers of people with dementia, Parker, Mills and Abbey (2008) found that multi-component interventions delivered significant outcomes for carers across a broad range of outcome measures including higher self-efficacy, lower depression, enhanced subjective wellbeing, and decreased carer burden.

CarersNSW (2017) found that counselling achieves the most positive health and wellbeing outcomes for carers when it is embedded within a multi-component intervention involving elements that include, in addition to counselling: educational interventions; in-home coaching; peer support; provision of respite; community linkages; and crisis assistance. Multi-component interventions may be more successful than individual interventions because carers are dealing simultaneously with 'a broad range of stressors' (CarersNSW 2017).

According to Strobel and Adams (2015), multi-component interventions to improve carer health and wellbeing can be grouped into three interlinked outcome clusters. This can be expressed as follows:

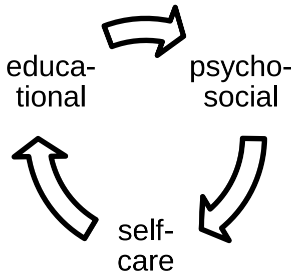


Figure 3: Promoting carer health and wellbeing: a multidimensional approach

Source: based on Strobel and Adams (2015)

3.2.2 Specific interventions

Research suggests that there is no 'one size fits all' intervention to support carers. Instead, there is evidence for specific interventions being effective for specific groups of carers (Thomas et al. 2017). Thus:

- Shared learning, cognitive reframing, meditation and computer-delivered psychosocial support may be effective for carers of people with dementia.
- Psychosocial interventions, art therapy and counselling may be effective for carers of people with cancer.
- Counselling may be effective for carers of people with stroke.

In keeping with this suggestion of the tailoring of interventions to specific groups of carers, Worrall et al (2018) showed a consistent pattern of evidence, generated over many years, which confirms the effectiveness of support groups for carers of people with mental illness. Professionally facilitated group work for carers of people with severe mental illness can assist them by: providing education and information in order to increase knowledge and understanding of the disorder; encouraging an atmosphere of mutual trust through which they could explore strategies for coping; and providing emotional support conducive to an open and honest sharing of feelings. Peer support groups were also found to be beneficial for carers of older adults with dementia living in their own home (Lauritzen et al. 2015).

In addition to tailoring interventions to specific groups of carers, there is evidence of beneficial outcomes for interventions that targets the specific needs of individual carers. If a carer is experiencing sleep disturbance, for example, interventions to improve sleeping would be of help to that carer (Hudson et al. 2010). An overall insight from the literature on the effectiveness of specific interventions is, therefore, that ‘there may be ways of designing interventions for supporting carers that have generic application, whilst acknowledging there will always be the need for individual variation’ (Hudson et al. 2010: 4).

The provision of respite care, either in the home or in a facility, has been a focus of many studies and the evidence is mixed in terms of its effectiveness in addressing carer burden and improving health and wellbeing (Vanderpitte et al. 2016; Victorian Government 2015). In a systematic review, Vandepitte et al. (2016) found that day care services are effective in decreasing caregiver burden and behavioural problems in persons with dementia, but they also accelerate the time of admission of~~to~~ the patient into nursing home care. The results of temporary residential admission are mixed: there are unexpected adverse effects on both carers and care recipients. Problems in generating evidence for respite care include:

- methodological challenges, linked especially to the difficulty of isolating for the effects of respite care
- ethical issues that arise when some respondents receive services and others not, which is essential for the establishment of control groups
- sampling issues, linked to the often poor awareness of services among carer cohorts, and the diversity of those who receive respite services (Brodaty and Gresham, cited in Williams and Owen 2009: 41).

3.2.3 The process of caring

In addition to focusing on types of intervention, studies also address the helping process. For example, based on a systematic review of the literature and a synthesis of findings, Duggleby et al. (2017) provide a framework – the Redefining Normal Conceptual Framework – that can be used to guide the development of support for carers. It suggests a five-step helping process with the following outcomes:

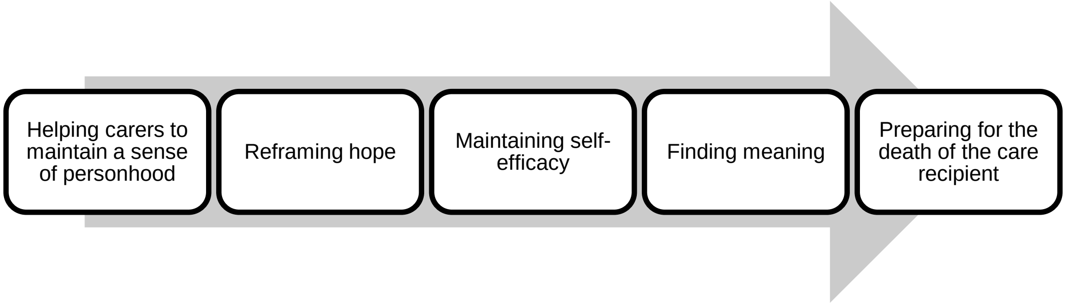


Figure 4: A framework for providing support to carers of people with cancer

Source: based on Duggleby et al. (2017)

The underlying principle of this Framework is that carers have to come to terms with the situation that confronts them before they are successfully able to connect with information and resources. Programs and interventions should be designed to support carers to ‘redefine normal’ so that they can achieve the outcomes of value to them and the people the care for. It is argued (Duggleby et al 2017) that if carers are able to redefine their reality in this way, then they are able to maintain their personhood, self-efficacy and hope. This helps them to prepare for all the changes that accompany the carer’s role and to prepare for the transition that also marks the end of their caring role i.e. the death of their loved one.

From the service providers’ point of view (Duggleby et al. 2017), carers of people with advanced cancer are best supported through the life-altering transition experience through the provision of timely information, supportive networks, and positive attitudes toward the caregiving they provide. Priority should be given to identifying the ‘disruptions’ that may ultimately impact carers’ abilities to continue caring.

With a focus on supporting carers once their caring roles have ended, Granaheim, Johansson and Lindgren (2014) found on the basis on a systematic review that adaptation to the new situation (the cared-for person’s move into a nursing home) can be facilitated if family carers continue to be recognised as partners in care. This includes having regular meetings with staff; and by professionals offering clinical supervision to deal with the emotional strain carers may be facing.

3.2.4 Aboriginal and Torres Strait Islander carers

According to the Census, 45,328 Aboriginal and Torres Strait Islander people identified as carers in 2011, an increase from 32,581 in 2006 (Taylor 2013). The rate of caring amongst the Aboriginal community of NSW is significantly higher than the non-Aboriginal community (13.6% compared to 11.4%). Mothers are most frequently the primary carer, followed by other female relatives. People take on caring roles due to necessity, cultural and family responsibilities, the importance placed upon care of older people, and considering caring to be spiritually important. Carers experience isolation and problems in accessing services to a much greater extent than non-Indigenous Australians.

Hokanson, Quinn, Schüz et al. (2018) conducted a systematic review of Indigenous carer functioning and interventions, and found little quality evidence around Indigenous caregiver functioning. Most studies contained numerous methodological weaknesses that compromised the reliability and validity of findings. Hill et al. (2012) recognised the need for research to address an apparent gap between official data on Indigenous disability and care provision, and the real-life experience of Indigenous disability and informal caring. These researchers also point to the need for research that explores the complexity of caring relationships, the contexts for caregiving, and the diversity of care situations.

In spite of these limitations, the available evidence suggests poorer health outcomes and a higher burden of care among Indigenous carers relative to non-Indigenous carers. At the same time, high levels of positive aspects of caregiving were reported in one of the six studies include in the review carried out by Hokanson et al. (2018).

Based on a review of the literature, Hill et al. (2016: 8) identify key factors that are common to supporting Indigenous carers in Australia, New Zealand and Canada:

- Support for carers to identify as carers.
- The need for access to culturally appropriate and timely information.
- The need for culturally safe services.
- Recognition by health and disability systems and broader society of the contributions of Indigenous carers.
- Communication and coordination among service providers, communities and caregivers.

Key studies examining the effectiveness of interventions to improve carer health and wellbeing are summarised in the table of evidence for this topic (Table 3) below.

Table 3: Table of evidence: Effectiveness of interventions to improve carer health and wellbeing

Authors	Study aims and methods	Findings	Implications
Hokanson et al. (2018)	Systematic review of literature on Indigenous caregiver functioning and the interventions that are effective in alleviating Indigenous caregiver distress. Peer-reviewed quantitative studies examining Indigenous caregiver functioning or evaluating Indigenous caregiver interventions were included. Only seven articles representing six studies met the full inclusion criteria.	The study confirms the view that, despite decades of research, there is a paucity of research on Indigenous carers and caregiving adopting quantitative approaches. Most studies contained numerous methodological weaknesses that compromised the reliability and validity of their findings. Available studies suggest poorer health and a higher burden among Indigenous relative to non-Indigenous caregivers. However, high levels of positive aspects of caregiving were reported in one study. A single intervention study suggests that poor health outcomes among Indigenous caregivers can be alleviated, though the quality and focus of this study was sub-optimal.	There is very little quality evidence around Indigenous caregiver functioning. Future research in this area would benefit from greater adherence to the standards of research that contribute to a strong and reliable evidence base.
Abrahams et al. (2018)	Systematic review and meta-analysis of studies examining the effectiveness of support interventions for carers of people with dementia. 22 studies were included in the review, and of these, 15 were included in the meta-analysis	A classification of outcomes of intervention was generated, namely that the interventions are aimed at having a positive effect on: • Carer burden • Carer depression • Carer health • Social support for carers. Interventions are successful in achieving these outcomes when offered within an effective multi-component intervention that includes education, skills training, counselling and support groups.	An effective multi-component intervention is beneficial to carers who experience burden, depression, health problems and social isolation. The literature presents a trend that a combination of counselling, support groups, education, stress and mood management or telephone support are important strategies within an effective multicomponent intervention. Putting in place such a multi-component intervention for carers of people with dementia helps to achieve the ultimate outcome – delaying care recipients' move into formal assisted living.
Hopkinson et al. (2018)	Systematic review and meta-analysis of studies examining the effectiveness of cognitive behavioural therapy (CBT) to reduce stress and anxiety in	Depression and stress were significantly reduced after CBT, while anxiety was not. Group formats were more effective than individual formats of CBT.	Group CBT provides small but significant benefits to reduce carers' depression and stress. The cost-effectiveness of therapy may be enhanced by limiting carer intervention to group therapy and to eight sessions.

Authors	Study aims and methods	Findings	Implications
	carers of people with dementia. 25 studies were included	Eight CBT sessions or fewer were equally as effective as more than eight sessions.	
Worrall et al. (2018)	Systematic review of studies examining the effectiveness of support groups for families and carers of people living with mental illness, and also for people living with mental illness. 57 articles were included	Objectives of carer support groups include: • to provide education and information in order to increase knowledge and understanding of the disorder • to encourage an atmosphere of mutual trust in which to explore strategies for coping • to provide emotional support conducive to open, honest sharing of feelings. There is a consistent pattern of evidence, over a long period of time, which confirms the effectiveness of mental health support groups for carers.	Further research is needed to help determine the mechanisms through which benefits are achieved, including the contributions made by professional facilitators to group outcomes.
Thomas et al. (2017)	A meta-review (systematic review of systematic reviews) examining the evidence for the effectiveness of interventions designed to provide support to carers A total of 61 systematic reviews were included	27 of the studies were of ‘high quality’, 25 of ‘medium quality’ and nine of ‘low quality’. 14 reviews focused on carers of people with dementia; four reviews each on carers of people with cancer and of people with stroke; three reviews considered carers people with various conditions at the end of life; and two reviews focused on the carers of people with mental health problems. For all carer groups, there is strong evidence for the effectiveness of providing education, training and information for carers. When active and targeted, such interventions increased carers’ knowledge and abilities as carers, with some indication that they might also thereby improve carers’ mental health or coping. Interventions with an information-provision focus for carers of people with dementia may also have a positive impact on subjective burden.	There is no ‘one size fits all’ intervention to support carers. Instead, there is evidence for specific interventions being effective in helping specific groups of carers. For example: • Shared learning, cognitive reframing, meditation and computer-delivered psychosocial support may be effective for carers of people with dementia. • Psychosocial interventions, art therapy and counselling may be effective for carers of people with cancer. • Counselling may be effective for carers of people with stroke. Research is needed that separates out different parts of multicomponent interventions and then models their unique impact.

Authors	Study aims and methods	Findings	Implications
Oldenkamp et al. (2017) ***Lifelines Informal Care Add-on Study* (Lifelines ICAS), the Netherlands**	The study (Lifelines ICAS) was initiated within the Lifelines Cohort Study. It aimed to better understand diversity in the caregiver population and to investigate the complex interplay among the characteristics of the caregiver, care recipient, and care situation and positive and negative caregiver outcomes.	The Lifelines Cohort Study is a large population-based cohort study in the north of the Netherlands established to facilitate research on the universal risk factors of multifactorial diseases and their modifiers A total of 11,651 Lifelines participants self-identified as informal carers and agreed to provide basic information about their care situation. A subsample of 965 informal caregivers participated in Lifelines ICAS and completed a comprehensive questionnaire about their care situation.	Large, longitudinal cohort studies enable the study of differences among carers, care recipients, and care situations, as well as the study of common characteristics and features across caregiver groups.
Corvol et al. (2017)	Systematic review of studies examining the impact of involvement in case management on the carers of people with dementia 12 studies were included that made use of randomized trials or were quasi-experimental studies designed to compare case management programs to 'usual care'.	The studies measured impacts on carer outcomes including burden (or strain or distress), satisfaction, health-related quality of life (or psychological health), depression, and social support. Seven studies identified at least one positive result for carers, and no negative effect of case management has been found. Characteristics associated with positive results for caregivers were a high intensity of case management and programs specifically addressed to patients with dementia.	Clinical case management programs can be beneficial for carers of dementia patients. Positive results for patients are achieved without increasing carer burden. Evidence can be strengthened through more accurate descriptions of contexts, of the intervention itself, and of its actual implementation, as well as through a careful choice of trial design and outcomes.
Trump and Mendenhall (2017)	Systematic review of studies that focused on how couples cope when one is diagnosed with cardiovascular disease. 25 studies met the study's inclusion criteria.	The mental and emotional wellbeing of partners is affected at an equivalent or more extreme rate than that of patients. Women reported on average higher levels of stress than men, and preferred more active roles in decision-making.	Care after a cardiovascular disease diagnosis needs to focus on the dyad of patient and partner – both members of the couple should be included in within the treatment regime.
Carers Australia NSW (2017)	Review of studies examining the effectiveness of psychological interventions for improving carer health and wellbeing	Approaches to counselling that have been studied include Cognitive Behavioural Therapy (CBT), strengths-based approaches, mindfulness and psychoeducation. Themes addressed in counselling include:	Counselling achieves the most positive health and wellbeing outcomes for carers when it is embedded within a multi-component intervention, involving elements that include, in addition to counselling: • education

Authors	Study aims and methods	Findings	Implications
		• stress management and self-care • coping with a crisis, such as a significant deterioration in care recipient's health • problem solving, caring skills and strategies • grief and loss issues • transition issues	• in-home coaching • peer support • provision of respite • crisis assistance • community linkages. All of these aim to address a broad range of stressors that may be present in the carer's life.
Duggleby et al. (2017)	A comprehensive literature review and metasynthesis was carried out, based on studies published in English between 2004 and 2014 that focused on the experiences of family carers of people with advanced cancer. 72 studies were included in the metasynthesis.	Family carers of persons with advanced cancer experience a 'life transition' that overwhelmingly and permanently alters their lives. Disruptions occurred in their environment (e.g. difficulty in getting out of the house), with respect to their roles, relationships and priorities, to their physical and mental health, and regarding their hopes for the future. The participants described a process of 'redefining normal', which consisted of coming to terms with their situation and re-connecting with others.	The study provides a framework – the Redefining Normal Conceptual Framework – that can be used to guide the development of support for carers. It suggests a five-step helping process with the following outcomes: 1. Helping carers maintain a sense of personhood 2. Reframing hope 3. Maintaining self-efficacy 4. Finding meaning 5. Preparing for the death of their care recipient. It is likely that carers will need to receive individualised support in order to 'redefine normal'. This metasynthesis and its findings provides a framework for further research.
Lashewicz, Shipton and Lien (2017)	Meta-synthesis of qualitative literature examining the experiences of fathers of children on the autism spectrum (ASD) 11 studies met the inclusion criteria and of these, six met quality appraisal inclusion criteria	Analysis of the literature suggests three main themes: • strong evidence of the theme of 'adaptation', which includes relief that accompanies a child's diagnosis with autism following a period of uncertainty, and engagement with the future • the importance of understanding the cultural context of the carers	There is a need for much greater research rigour when qualitative approaches are adopted in researching the experiences of carers. There is a need for father-oriented resources that recognise the role of fathers in the lives of children's with ASD.

Authors	Study aims and methods	Findings	Implications
		- embracing the new opportunities that arise from raising a child with ASD.	
Vandepitte et al. (2016)	Systematic review of studies examining the effectiveness of respite care in supporting carers of persons with dementia Studies were only included if they generated high quality evidence, that is, if they were randomized controlled trials, quasi-experimental studies, pre-test-post-test studies without a control group or cohort studies. 17 studies met these inclusion criteria.	Day care services are effective in decreasing caregiver burden and behavioural problems in persons with dementia, but they also accelerate time to nursing home admission. The results of temporary residential admission are mixed. There are unexpected adverse effects on both carers and care recipients. High-quality comparable evidence on community-based respite care is still lacking. Evidence from earlier qualitative studies yielded positive results.	There is a need for research that measures the impact of respite care on carer wellbeing, on the care recipient, and on the use of health care resources. High quality research conducted within in-home respite care programs would be especially valuable
Greenwood and Smith (2016)	Narrative review of studies published between 1996 and 2016 that focused on the experience of carers who were 75 years and older. 18 relevant studies were found from all over the world.	There was a clear discrepancy in findings: some studies suggested that caring was more challenging for very old carers, while others found that older carers may be better equipped for the role than younger carers. Similar to previous findings, qualitative studies tend to report more positive aspects of caring than quantitative ones. There is insufficient evidence to support the view that older carers would benefit from interventions tailored specifically for them.	There is a dearth of research specifically examining the difference in caring experiences of younger and older carers. The finding that qualitative and quantitative studies yield different findings themselves with respect to the carer experience should be acknowledged in any future research.
Corry et al. (2015)	Systematic review of systematic reviews on interventions for carers of people with chronic conditions. All systematic reviews published between 1990 and 2014 were included. Papers were included if they reported a systematic review of	The eight reviews were of relatively high quality since they evaluated the quality of the included studies using acceptable criteria. Most of the interventions studied were complex, comprising many components. The challenges of recruitment and loss at follow-up is a potential source of bias.	Despite the heavy dependence of health services on the caring capacity of carers, there remains a limited number of systematic reviews investigating the effectiveness of interventions designed for carers of people with chronic conditions. Education, support and information-giving interventions warrant further investigation among a wider range of caregiver groups.

Authors	Study aims and methods	Findings	Implications
	interventions for caregivers of people with chronic conditions. 8 studies met the inclusion cfriteria	Findings support the use of education and support interventions to improve carer quality of life; and the use of active information interventions to reduce depression and burden of care.	
Yusefu-Udechuku et al. (2015)	Systematic review and meta-analyses of RCTs of interventions delivered by health and social care services to family or friends who provide support to someone with severe mental illness. 21 RCTs were included in the review. Outcome data were according to: end of intervention, up to 6-month follow-up and longer than 6-month follow-up.	Findings of this review are consistent with previous reviews: psychoeducation and support may be beneficial to those caring for people with severe mental illness. Nonetheless, the quality of evidence is low: • Very low-quality evidence of a large effect of psychoeducation on the experience of caregiving. Enhanced psychoeducation had a moderate effect on the experience of caregiving when compared with standard psychoeducation at the end of the intervention • Very low evidence of a large effect of support groups on the experience of caregiving at the end of the intervention • Moderate-quality evidence of a large effect of problem-solving bibliotherapy on psychological distress at the end of the intervention and up to six months later. Carers of people with severe mental illness, including schizophrenia spectrum disorders, psychosis, schizophrenia and bipolar disorder, benefit most from interventions that are delivered early, that is, within the first episode of psychosis.	Interventions for carers should be considered as part of integrated services for people with severe mental health problems. There is value in assessing the experience of caregiving, levels of burden and psychological distress, and the quality of life of people caring for someone with severe mental illness, including psychosis, in routine practice. For improved research, studies should: • be registered in advance • be reported in full to avoid reporting biases • be rigorously designed and clearly report information about the carer and patient participants, the interventions, comparison group and the primary outcomes of interest • take into consideration previous research regarding the most beneficial components of carer-focused interventions.
Victorian Government (2015)	Literature review to identify and document evidence in relation to the use of respite to support the carers of palliative care patients. An additional aim was to assess whether respite provision improves the efficiency of the health system more broadly.	There are limited RCTs that support the efficacy of respite in improving carer outcomes. Quasi-experimental and/or descriptive studies do suggest that respite has benefits for carers of palliative care patients. Support for carers of palliative care patients goes beyond the provision of respite. A more holistic approach would be based on designing an effective package of services	A package of services – incorporating respite – for carers of people of palliative care patients would include: • Understanding carer needs and challenges and assessing service preferences • Addressing risk factors for adverse carer outcomes

Authors	Study aims and methods	Findings	Implications
		and ensuring that these are implemented systematically. Carer needs identified in the literature include: • Physical needs, such as strength to lift the patient • Training and information regarding safe procedures for caring for the patient • Psychosocial needs, including supports to prevent isolation and conflict resolution • Cognitive, including mental breaks and respite from the illness • Effective communication and continuity of care. In order for patients to receive optimal care the mental and physical health of carers needs to be addressed.	• Planning, implementing and evaluating support strategies An outcome to strive for would be a palliative care system that provides the optimum mix and number of interventions that enables carers to maintain their resilience and continue for as long as possible in their roles.
Lauritzen et al. (2015)	Systematic review of qualitative studies seeking to understand the role and value of support groups for carers of older adults with dementia living in their own home. Five studies were included.	Support groups provide benefits in three major areas: • Emotional support for carers • Support to face the challenges of caregiving • Embracing the future.	Peer support is beneficial for caregivers. It provides a source of positive emotional support and a means of venting negative feeling and gaining help to address issues in the everyday life of caring for older adults with dementia. Research could focus more on understanding the meaningfulness of group participation to carers.
Greenwood and Smith (2015)	Systematic review of published literature on the experiences of male carers in accessing formal and informal supports. The focus was on identifying barriers and facilitators.	A total of seven published studies met the inclusion criteria, all from North America. Positive past experiences and the availability of supports are facilitators in accessing support. Barriers to accessing supports can be linked to service-related issues, such as costs; and male carer attitudes, including reluctance to cede responsibility for caring to formal services.	More research is needed on the experiences of male carers
Huis in Het Veld et al. (2015)	Meta-review of systematic review studies that have examined the effectiveness of interventions that support self-	Evidence exists for the effectiveness of professional self-management support interventions targeting psychological wellbeing on stress and social outcomes of informal caregivers. In addition, evidence exists for the	There is evidence for the effectiveness of a number of professional self-management support interventions

Authors	Study aims and methods	Findings	Implications
	management of carers of people with dementia. Self-management interventions help carers to manage the consequences of dementia in daily life. Ten high quality studies were included	effectiveness of information-giving interventions that aim to increase carers' abilities and knowledge. Limited evidence was found for the effectiveness of interventions targeting techniques to cope with memory change on coping skills and mood, or of interventions targeting information on the carer outcomes 'sense of competence' and 'decision-making confidence'.	targeting the psychological wellbeing and information needs of carers of people with dementia. Psycho-education was a component of most of the self-management support interventions that were found to be effective in this meta-review. Longer and more intensive interventions were associated with greater effects.
Granaheim, Johansson and Lindgren (2014)	The study investigated the experiences of carers of people with dementia once they relinquished care to a nursing home. Systematic review of studies published in English from 1992 to 2012 that used qualitative empirical designs, were peer-reviewed and were given ethical approval. In their analysis, the researchers used a meta-ethnographic approach. Ten studies met the inclusion criteria.	Carers felt unprepared, lonely and filled with contradictory emotions when confronted with the decision to relinquish care. Many held themselves responsible for the decision to opt for nursing home care, since the persons with dementia could no longer express their own will. The decision was usually forced by a crisis, such as falls. Many carers felt they were poorly informed about the progress of the disease, and handled this uncertainty in various ways, including making their own inquiries. Adaptation to the new situation can be facilitated if family carers are recognised as partners in care, including that they have regular meetings with staff; and by offering staff clinical supervision to deal with the emotional strain of carers.	Further research is needed to better understand the 'relinquishing' processes carers go through. The process of relinquishing care is similar to a crisis process, which starts with a turning point, followed by a coping phase and finally the outcome of the process. One of the changes is that the carers' role becomes one of monitoring the quality of care at the nursing home and being a spokesperson for the patient. An ethnographic and meta-ethnographic approach to research would be an important means of better understanding the lived experiences of carers. The nature of this research is that it is participatory.
Taylor (2013)	Review of the literature to examine practical ways to overcome isolation for Aboriginal and Torres Strait islander carers	According to the Census, 45,328 Aboriginal people identified as carers in 2011, an increase from 32,581 in 2006. The rate of caring amongst the Aboriginal community of NSW is significantly higher than the non-Aboriginal community (13.6% compared to 11.4%). Mothers are most frequently the primary carer, followed by other female relatives. People take on caring roles due to necessity, cultural and family responsibilities, the importance placed upon care of older people, and considering caring to be spiritually important.	There is a major gap in the literature regarding formal evaluation of programs, services and resources for Aboriginal and Torres Strait Islander carers in Australia. To better understand Aboriginal and Torres Strait Islander carers, focus should be placed on gaining insights into: • the lived experience of carers, including that carers often look after more than one person at the same time

Authors	Study aims and methods	Findings	Implications
		Carers experience isolation and problems in accessing services to a much greater extent than non-Indigenous Australians. A key cultural practice associated with caring is ‘yarning’, which involves having a conversation with others and/or telling stories.	• barriers to seeking support and accessing services, including not identifying as a ‘carer’ • means of providing support, which can be categorised as ‘downstream’ (individual level); ‘midstream’ (group or community level); and ‘upstream’ (broader context, models, systems, policy, legislation and infrastructure). Comparisons can be made with international literature focusing on Indigenous peoples from countries such as New Zealand, Canada and the USA.
Hill, Cass, Newton and Valentine (2012)	Literature review and data analysis in order to discover what information is known, what further information is needed, and how further information can best be obtained, about Indigenous people who are providing informal care for a person due to disability or ageing?	There are higher rates of informal caregiving in the Indigenous compared to the non-Indigenous population. A higher prevalence of caring has been attributed to higher rates of disability, long-term health conditions and the earlier onset of chronic illness. Compared to other population groups, Indigenous people may have differing perceptions about the nature of disability and chronic conditions, and how healthcare and community services might be accessed and what their benefit might be. In Indigenous communities, the provision of informal care is usually embedded within the everyday responsibilities and duties of family life. People providing support, help and assistance to family members or friends with a disability, chronic illness or frailty associated with old age may not as ‘carers’.	There is a gap between official data on Indigenous disability and care and the real-life experiences of Indigenous disability and caregiving. There may be value in identifying two groups of Indigenous carers: ‘identified carers’ and ‘potential carers’. Recommendations for research, policy and practice may differ between the two groups of carers. Qualitative research methods have a particularly important role to play in exploring the complexity of caregiving relationships and the contexts of caring. No national data on the nature and extent of barriers to social and economic participation for Indigenous carers currently exists. More research is needed to identify specific issues that affect Indigenous carers in different communities.
Hudson, Remedios and Thomas (2010)	Systematic review examining the effectiveness of psychosocial interventions for family carers of palliative care patients 14 studies met the inclusion criteria	Interventions that were evaluated included psychoeducation, psychosocial support, carer coping, symptom management, sleep promotion and family meetings. Interventions aimed towards psychoeducation, problem-solving and cognitive restructuring have demonstrable effects on carer well-being.	Empirical inquiry on effective ways to provide psychosocial support to family carers is still in its infancy. Unless this matter is redressed there will continue to be disconnect between what is advocated in policy (that family carers’ needs are assessed and adequately responded to) and what actually happens in clinical practice (health professionals operating without a suitable evidence base to support family carers).

Authors	Study aims and methods	Findings	Implications
		Interventions targeted to individual carers – such as therapy for sleep deprivation and training in problem-solving skills – are effective. Interventions based on an individual approach are more likely to have significant effects for carer burden and well-being; interventions based on group approaches work well for building carer competence.	Unless there is a major research investment in this area, the claim that palliative care services provide family carers with effective support will continue to be disputed.
Williams and Owen (2009) **Study carried out by the Centre for Health Service Development (on commission from the Australian Government Department of Health and Ageing**	The study aimed to assemble and assess the evidence for interventions to support carers. Researchers reviewed Australian and international academic and practice literature, and conducted a concurrent analysis of policy and practice in Australia.	There is good evidence for the effectiveness of multi-component interventions. The overall evidence on educational and psycho-educational interventions is good, especially for carers of people with dementia, mental illness and disability. The overall evidence on the value of counselling and psychosocial interventions is positive. However, some studies and reviews report no measurable effects. The evidence on respite care is mixed. Although there have only been a small number of studies investigating case management and care coordination and their impact on the carer, the available evidence is promising.	The researchers promote a program of research that understands and Identifies the needs of Australian carers, produces the strong evidence, uses evidence to shape programs that meet the needs of carers Effective services, based on stronger evidence, can communicate their findings which contributes to better policy to support even more effective services.
Edwards et al (2008) **Families Caring for a Person with a Disability Study (FCPDS)**	The study was based on a nationally representative telephone interview survey conducted in 2006 of carers (N=1002) who were caring for a person with a disability and who were receiving the Carer Payment and/or Carer Allowance in Australia. The study examined the effect of caring on family and social relationships; documented the social, emotional, physical and financial impacts on families of caring for a person with a	Sixty per cent of carers reported that they cared for the person with a disability for more than 100 hours per week. Thirteen per cent of primary carers cared for two or three people with a disability. In addition, almost one in three cared for at least one child as well as the person with a disability (who could also be a child). Carers and their families experienced significantly worse mental health, vitality and physical health, and suffered higher rates of depression than the general population. Carers raising children (both with and without a disability) or those caring for multiple family members with a disability were at particular risk of worse mental health outcomes.	There are substantial social, emotional and economic costs of caring for a person with a disability, not only for the primary carer but also for the family. Particular focus needs to be placed on: • Ensuring that carers have access to mental health screening and supports • Families with multiple care responsibilities • Families caring for a person with psychiatric disabilities The challenge for policy makers and the Australian community is to develop policies and an environment

Authors	Study aims and methods	Findings	Implications
	disability; and examined the effect of caring on labour force status.	Compared to families from the general population, a greater proportion of carers' families endured financial hardship. Around one in five had no support; those that did receive support often had disagreements about caring and problems of cooperating with formal services.	that minimise social, emotional and economic costs of caring for a person with a disability.
Parker, Mills and Abbey (2008)	Systematic review to assess the effectiveness of interventions that assist carers of people living with dementia in the community The review considered any meta-analyses, systematic reviews, randomised control trials, quasi-experimental studies, cohort studies, case control studies and observational studies without control groups, published from 2000 to 2005. 40 studies were accepted for inclusion.	Effectiveness was analysed according to four categories of intervention: • Psychoeducational – positive results, but not significant in terms of wellbeing, self-efficacy or health; small but significant for depression and caregiver burden • Support – small but significant improvement on carer burden • Multi-component – significant outcomes across a broad range of outcome measures including self-efficacy, depression, subjective wellbeing and burden. • Other interventions – included the use of exercise or nutrition; case management; computer aided support intervention, all with mixed results. There appears to be little benefit from interventions which simply refer caregivers to support groups, only provide self-help materials or only offer peer support.	Evidence supports the use of well-designed psycho-educational or multi-component interventions for caregivers of people with dementia who live in the community. There are wide-ranging outcome measures reported in the literature. Best practice guidelines should help to determine the most appropriate outcome measures for the intervention design. Priorities for future research in this area include: • Well-designed and conducted RCTs that have adequate sample sizes, well-defined intervention and control groups and adequate follow-up periods. • Interventions which are conceptually and theoretically sound. • Outcome measures that adequately measure the constructs within the intervention. • Outcome measures that are reliable and valid within the population studied.

3.3 Directions for future research

In order for research on carer health and wellbeing to develop, studies should take into consideration existing findings regarding the most beneficial components of carer-focused interventions (Yusefu-Udechuku et al. 2015). Future research can, for example, build on the insights of Taylor (2013), who has provided a higher order classification for carer support interventions: ‘downstream’ (individual level); ‘midstream’ (group or community level); and ‘upstream’ (broader context, models, systems, policy, legislation and infrastructure). Use of a framework such as this can assist in research design and methodology.

Whenever feasible, longitudinal studies should be designed. As Oldenkamp et al. (2017) have shown in the Netherlands, large, longitudinal cohort studies enable the study of differences among carers, care recipients, and care situations, as well as the study of common characteristics and features across caregiver groups. Pioneering research of this nature has been undertaken in Australia with a focus on carers and employment (see Hill et al. 2008).

High quality evidence for the effectiveness of specific interventions to improve carer health and wellbeing, such as skills training, counselling or support groups, would benefit from research designs that separate out different parts of multi-component interventions and model their unique impact (Thomas et al. 2017).

There is a need for further research on care coordination interventions, such as providing respite care and home nursing from within the formal care system (Strobel and Adams 2015). It would be advantageous for this research to be solidly grounded in the current consumer-directed care policy contexts.

Corry et al. (2015) write that education, support and information-giving interventions warrant further investigation among a wider range of caregiver groups. In particular, there is a need for high quality research on all aspects of caring involving Aboriginal and Torres Strait Islander people.

The finding by Greenwood and Smith (2016) that qualitative and quantitative studies yield different findings with respect to the carer experience should be acknowledged in any future research.

4 Information and community awareness

4.1 Issues and debates

4.1.1 Carers' access to information

Carers' access to information is closely tied to the access they enjoy to supports that would help them address their health and wellbeing needs. Put differently, the provision of information contributes in the same way as other supports – discussed in detail in Chapter 3 of this report – to enhancing the carer experience and helping informal carers to address issues such as their need for specific skills and ameliorating carer burden.

In order for carers to access the information that is directed towards them by governments and service providers, people who have taken on a responsibility with regard to informal caring need firstly to identify themselves as 'carers'. As highlighted by Hill et al. (2016: 50):

> *Many carers do not see themselves as carers. They view the support they provide as part of their role as a spouse, daughter/son, parent, relative or friend. This can result in carers not accessing information and services.*

The existence of a carer 'identity' also assists members of the broader community to develop awareness of carers. Despite the increase in policies and programs focusing on carers and informal caring, many people remain as 'hidden carers' (Knowles et al. 2016).

At the national level, the Australian Government committed funding for the design of an 'Integrated Plan for Carer Support Services' (Commonwealth of Australia 2018). Developed to reflect the Australian Government's priorities for carers, it outlines actions to improve access to information and services specifically for carers. The Plan has two key stages:

- The first stage was the design and implementation of Carer Gateway, launched in December 2015. This included a website (www.carergateway.gov.au) and a national contact centre dedicated to the delivery of carer-specific information. Its purpose is to provide carers with a recognisable source of clear, consistent and reliable information that would enable them to better navigate the system of support and services.
- The second stage involved working with the sector (including carers, service providers, peak bodies and individuals with carer-specific expertise) to co-design an integrated system of carer-specific supports and services that would be better positioned to support Australia's carers into the future.

An issue that may be a source of conflict between carers and service providers is the professional ethic of patient/client confidentiality: a strong sense of protecting the confidentiality of their clients may make it difficult for providers to share information with family members, even primary carers. For example, in a systematic review of research, Bee, Barnes and Luker (2008) showed that many studies pointed to a perceived reluctance among health professionals to provide carers with information and guidance.

4.1.2 Community awareness of caring

Community awareness of carers and the role of informal caring is essential because such acknowledgement is the first step towards society placing a value on their contributions. At the same time, raising the community's awareness, and maintaining it, is challenging because, as Carers NSW (2016: 14) has found, on the basis of an analysis of carers surveys carried out in NSW for 40 years:

> *No person can ever know what it is like to be a carer until they take on the role for themselves. Such lack of understanding can prevent individuals (and even large groups or companies of people) from proactively searching for and implementing strategies that may assist in alleviating inequalities between carers and their non-caring peers (e.g., directly addressing financial disadvantage, promoting equity in the workplace, providing social support to assist with lower levels of wellbeing).*

Although relevant to all aspects of caring dealt with in this report, the predominance of women carers and the theorising about this (the 'gendering of care work', as described by Bondi 2008) is relevant to this priority focus in the NSW Carers Strategy – community awareness that contributes to the feeling that carers have that the broader community understands and values their experience. Growing in importance since the 1970s, feminist theory and research has helped to, as Yeandle et al (2017: 6) describe it, 'remove the cloak of invisibility that has often surrounded care and caring'. Based on a comprehensive overview of countries from all regions of the world, Ferrant et al. (2014: 2) found that women spend on average 'between three and six hours on unpaid care activities, while men spend between half an hour and two hours. Hence gender inequalities in unpaid care work are observed all around the world, even if there are regional variations. Overall, women spend more time on unpaid care activities than men representing on average two to ten times that of men's.'

Drawing on debates in the academic literature, Bondi (2008) writes that feminist accounts of women's paid and unpaid caring work have noted how the gendering of care work is closely linked to the devaluation of care, which contributes in turn to the perpetuation of gender inequalities.

Surveys carried out by Carers NSW (2016: 12) have shown consistently that carers place a priority upon being recognised and acknowledged. These surveys provide evidence of carers expressing feelings of being 'undervalued and underappreciated'. The community would also benefit from knowing that caring is addressed in legislation and policy, for example in NSW, the *NSW Carers (Recognition) Act 2010* and the NSW Carers Strategy 2014-2019. Awareness of carers, or the lack of it, also extends to service providers (e.g. Greenwood et al. 2010).

4.2 Evidence

On the basis of a systematic review, Adams, Boulton and Watson (2009) found a generally poorly developed and theorised concept of 'carers' information needs' in the papers focusing on the topic. Washington et al (2011) conducted a literature review on the information needs of carers of people with chronic health conditions and found:

- Unmet information needs are prevalent among informal carers of older adults with chronic illness.
- Carers wish to be better informed on a wide range of issues, from biological and medical issues to information concerning service availability. The most commonly identified need was for basic disease information.
- Medical jargon is not the only barrier to comprehension – carers need individualised help to process the information.
- Timing is important when it comes to information provision – timing relates to changes in information needs over time and the need for proactive information provision.

These findings concur with those of Bee, Barnes and Luker (2008), who focused on carers of cancer patients near the end of life. Carers expressed the need to improved information on medication management, greater knowledge of disease progression, increased preparation for the physical demands of caregiving, information on the availability of nursing aids and local resources, and how to perform the non-medicinal elements of caregiving, such as patient nutrition, positioning and bathing. In terms of information delivery, carers expressed the desire for increased skills-based training, and more internet support groups, telephone help lines and community college courses (Bee et al. 2008).

As regards the effectiveness of information-provision, Corry et al. (2015) demonstrate on the basis of a systematic review that the use of active information interventions helps to reduce carer depression and burden of care. In similar vein, Thomas et al. (2017), whose work is discussed in greater detail in Chapter 3 of this report, find strong evidence for the effectiveness of education, training and information-provision in supporting carers. Such interventions should ideally be proactive and targeted to each carer's specific needs so as to increase caregiving knowledge and ability. There is some evidence which suggests that information interventions have positive outcomes on carers' mental health, coping abilities and burden (Thomas et al. 2017).

Bee et al. (2008) found evidence for a perceived reluctance among health professionals to provide carers with information and guidance. Barriers to this sharing of potentially useful information include professional concerns about confidentiality in the case of patient-specific information; providers having insufficient training in supporting, and thus sharing information appropriately with) carers; and the resourcing required to assist carers to process the information they have received (Greenwood et al. 2010; Washington et al. 2011).

A framework for the information needs of carers is provided by Adams, Boulton and Watson (2009), based on a systematic review of studies focusing on carers of cancer patients. This typology, summarised in Table 4 below, may be applicable to other carer groups as well.

Table 4: Framework for the information needs of carers of cancer patients

Category of information	Examples of sub-categories
Treatment-related information	Side effects Nutrition Practical aspects Complementary or alternative therapies
Diagnosis and prognosis related information	General development of the illness/prognosis Diagnostic tests Chances of survival
Coping information	Dealing with the psychological impact of the disease on the patient Dealing with own emotions Living with uncertainty
Self-care and homecare	Help to optimise patient’s comfort Help to maintain a patient’s independence Information on the availability of care services
Cancer-specific information	Understanding oncological terminology Symptoms Causes and risk factors
Impact on the family	Restrictions on activities Psychosocial impact on family in general Role changes
Support	Availability of social support, support groups and programs
Relationship with partner	Practical impact Transport Settling of affairs, including wills
Hospital care	To be kept informed about changes in care Who is the designated staff or physician to whom they can turn Referrals to medical services
Follow-up and rehabilitation	Post-surgical support and information Continuing contact after discharge Follow-up information from the hospital

Source: Adams et al. (2009: 181-182)

A framework of this nature can be useful for practice and future research, and supports the findings from the research conducted by Corry et al. (2015) and Washington et al. (2011) that carers of family members with chronic health conditions express the need to be better informed on a wide range of issues, and that many would benefit from the provision of individualised help to process the information they receive.

On the basis of a study carried out in NSW (see Table 2), Strobel and Adams (2015) found that there is a need for improved modes of information provision to carers, including how to communicate the availability of services. Similarly, Washington et al. (2011) suggest that there is value in having in place a health information delivery system that focuses on:

- **General information** (basic information about the illnesses and their prognosis) which can be provided in print form or online. Optimising online publication, which suits many carers, also requires ensuring that the information is accurate, up-to-date and user-friendly.
- **Specific information** tailored to each carer's specific needs and presented in a way that carers could comprehend and apply.

In recent years, rapid developments in information technology and the role of the Internet have impacted upon carers' access to, and use of, information. In keeping with a research interest in the role of the Internet as a source of information for carers, Kinnane and Milne (2010) found that the Internet does indeed function often as a primary source of information for carers of people with cancer. At the same time, relying on it depends on the carer being able to critically appraise the information and process it within the context of their situation.

Day (2015) estimated that there are more than 388,800 young Australians providing care, support or assistance to family members with chronic illness or disability. Research into the extent and nature of informal young adult caregiving in Australia showed that young carers are not recognised in policy or practice as a distinct carer cohort requiring specifically targeted resources to support their transition towards adulthood (Day 2015). At the same time, based on the findings from a cross-national study, Leu and Becker (2017) found that awareness in Australia of young carers is more advanced than in most countries (second only to the UK). These authors point to some of the features of this awareness: crucially in both countries, non-government organisations (NGOs) played a key role in raising awareness and campaigning for change. These organisations also played a strategic role in steering and shaping public discourse and policy developments through their steady engagement with policy-makers and politicians.

Drawing upon these findings, Leu and Becker (2017) generate a classification framework for the 'level of awareness' of young carers that can fruitfully applied to carers as a whole, with seven levels from very high (1) to very low (7). This classification system is summarised in Table 5.

Table 5: A classification system for countries' awareness of young carers as a distinct social group

Level	Quality	Characteristics	Countries
1	**Incorporated or sustainable**	Extensive awareness at all levels of government and society Sustained policies and interventions aimed at meeting young carers' needs Clear legal rights	none
2	**Advanced**	Widespread awareness and recognition among public, policy makers and professionals Extensive and reliable research base Multiple dedicated services and interventions nationwide	United Kingdom
3	**Intermediate**	Some awareness Medium-sized research base Some dedicated services and interventions	Australia Norway Sweden
4	**Preliminary**	Little public or specialist awareness and recognition Limited research base, but growing Few dedicated services and interventions	New Zealand Germany
5	**Emerging**	Growing public or specialist awareness and recognition Small but growing research base No specific services, but other services may be applicable	United States Ireland The Netherlands
6	**Awakening**	Embryonic awareness of young carers as a distinct social group	France Greece
7	**No response**	No apparent awareness or policy response to young carers as a distinct social group	All other countries

Source: Leu and Becker (2017: 752)

As can be seen from the table above, Australia rates highly on an international scale in terms of awareness of young carers as a distinct social group. The methodology adopted by the researchers is also useful in that it draws attention to carer awareness (for all carer groups) as encompassing a focus on:

- awareness and recognition among **policy makers and professionals**
- awareness and recognition within the **general public**
- carers having **legal recognition and rights**
- a carer-focused **research base**, which itself can be extensive and reliable (as it is in the UK), or small but growing
- **dedicated services and interventions** and their availability nationwide.

Greenwood et al (2010) studied the awareness that General Practitioners (GPs) have of family carers and their issues, as well as their perceptions of the barriers and enablers to service-provision. The study found that the majority (89%) of GPs felt insufficiently trained in supporting carers. Less than half (45%) were confident that they could identify carers in their practice. A few (9%) regarded carers as 'sometimes a barrier in managing the healthcare of the cared-for person'. Maintaining the confidentiality of the care recipient was recognised as difficult by the majority (92%) of the GPs in their conceptualisation of the role or involvement of carers in the lives of their patients.

The table of evidence (Table 7) of empirical studies focusing on carer access to information and community awareness of carers follows.

Table 6: Table of evidence: Carer access to information and community awareness of carers

Authors	Study aims and methods	Findings	Implications
Leu and Becker (2017)	The study aimed to examine the awareness within countries of young carers. The researchers drew on published research, grey literature, policy documents and the authors' own engagement in policy and practice networks for young carers and their families in several countries.	Whilst a few countries have identified and responded to the needs of young carers, others have been very slow to respond. Most countries in the world appear to have done little, if anything at all. In the UK and Australia, where support for young carers is the most developed, NGOs have played a key role in raising awareness and campaigning for change. They have also played a strategic role in steering and shaping public discourse and policy developments through engaging with policy-makers and politicians. In order for them to be able to carry out this role, they have drawn upon research findings that are specific to their countries. Key to this research has been including young carers up to the age of 24 in the definition of, and service delivery to, young carers.	The existence of a robust country-specific research evidence base provides an important foundation for policy developments and service responses addressing younger carers. There is value in developing an international community of research and practice.
Day (2015)	Narrative review to illuminate the existence, extent and nature of informal young adult caregiving in Australia The study included peer-reviewed output published between 1990 and 2014	There are more than 388,800 young Australians providing care, support or assistance to family members enduring chronic illness or disability. Young carers are not recognised in policy or practice as a distinct carer cohort requiring specifically targeted resources to support their transition towards adulthood. Few Australian resources targeted the specific experiences of young adult carers.	Without suitable recognition and targeted support, young adult carers may experience significantly reduced future life opportunities. Future research would benefit from being grounded in current debates and perspectives on caring, such as clinical perspectives, carers' right perspective and the social capital perspective.
Strobel and Adams (2015) **Brokered by the Sax Institute for the NSW Ministry of Health**	The researchers carried out an evidence check/rapid review in order to examine best practice interventions that influence carers' access to services. The focus was on systematic review studies published between 2010 and 2015 in English.	Initiatives that enable carers to gain access to services can be grouped into two approaches. **Primary health care interventions** – The role of GPs is crucial. GPs need skills to become more attentive to the needs of caregivers as well as care receivers. Provision of carer information resources such as information packs and service directories is also important. A key factor in primary care access is caregivers' perceptions of their role and responsibilities.	There is a lack of high-quality research that could help to determine which interventions improve carers' access to services. Studies are needed that indicate the optimum point of time for provision of services and which services would break down barriers.

Authors	Study aims and methods	Findings	Implications
	A total of 105 systematic reviews and 57 original investigations were included.	**Care coordination interventions** – include providing home care (e.g. home-delivered meals and respite), health service patient interventions, and involvement of the voluntary sector e.g. information, telephone help lines, befriending and carers' support groups.	There is a need for improved modes of information provision, including how to improve communication of service availability. Training of health care providers needs to receive attention, since the systematic reviews highlighted poor skills of care staff in providing information and support to carers and acknowledging their roles in care.
Harrop et al. (2014)	Qualitative study carried out in the UK to explore the information and support needs of family carers, as perceived by carers and nursing staff The methodology included four focus groups with Clinical Nurse Specialists, healthcare assistants, former and current carers at a hospice in the UK,	The research highlights care situations where carers experience uncertainty and could benefit from greater information or training, Three main themes emerged from qualitative analysis: • Developing knowledge and competence of carers • Facilitating the preparedness of carers • Supporting role recognition (as carers) and confidence building in that role	The researchers recommend an integrated information provision approach which addresses the three themes identified. There is an opportunity to develop an information pack for carers that provides practical information, advice and tips; it would also direct carers to think about more complex topics that they could request further information from professionals.
Wilkens et al. (2013)	Evaluation of a program conducted in Western Australia to provide information and support to parents and carers of children with Foetal Alcohol Spectrum Disorder (FASD)	The majority of carers gained information on FASD through contact with other carers and attendance at meetings organised by foster care services. The majority of carers accessed information and resources via the internet rather than from printed materials. Health professionals were identified as the main source of information specific to a child. The barriers in finding specific information related both to gaining access to health professionals and in the quality of information provided by health professionals and child protection workers. Parents and carers expressed a preference for audio-visual resources, rather than printed materials, and for resources containing Australian content. The carers indicated that their needs for general information about FASD would best be met by face-to-face workshops, testimonials and information on effective interventions based on real life experiences.	Further research is indicated to identify the information needs of Aboriginal carers in both metropolitan and regional centres and to evaluate targeted resources. Further research is also required to investigate the knowledge and attitudes towards FASD of child protection workers and to develop and evaluate specific interventions or processes to improve communication between the welfare sector and health professionals.

Authors	Study aims and methods	Findings	Implications
Washington et al (2011)	Literature review on the information needs of carers of people with chronic health conditions All studies from 2000 to 2009 were included in the search and 62 articles met the inclusion criteria	Unmet information needs are prevalent among informal carers of older adults with chronic illness. Carers wish to be better informed on a wide range of issues, from biological and medical issues to information concerning service availability. The most commonly identified need was for basic disease information. Medical jargon is not the only barrier to comprehension – carers need individualised help to process the information. Timing is important when it comes to information provision – timing relates to changes in information needs over time and the need for proactive information provision i.e. to know what to expect in the future so as to better prepare themselves.	There is value in having in place a health information delivery system that focuses on: • General information (basic information about the illnesses and their prognosis) which can be provided in print form or online. Optimising online delivery, which suits many carers, involves ensuring information is accurate, up-to-date and readable. • Specific information tailored to carers' specific needs and presented in a way that they could comprehend and make use of. Exploratory and qualitative research has an important role in helping to better understand the information needs of carers.
Greenwood et al (2010)	The UK study aimed to identify general practitioners' (GP's) awareness of family carers and their issues, as well as perceptions of the barriers and enablers to provision of services. Self-completed questionnaires (N=78) delivered at a series of workshops	GPs lacked confidence in their role in supporting carers (only 11% said they were confident) and the majority (89%) felt insufficiently trained in supporting carers. Less than half (45%) were confident that they could identify carers in their practice. A few (9%) regarded carers as 'sometimes a barrier in managing the healthcare of the cared-for person'. Maintaining the confidentiality of the care recipient was recognised as difficult by the majority (92%) of the GPs. There is an apparent gap between what GPs think carers might like and what they offer them.	Further investigation is needed both to determine how best to train and facilitate GPs and general practice teams in their role in supporting carers and to identify what carers need and want from general practice. Identifying carers' leads or champions amongst practice staff is possibly one way forward. These would be GPs who can recognise the needs and difficulties of carers and offer them information and respond to their enquiries. They could assume much of the responsibility for 'signposting' carers'.
Kinnane and Milne (2010)	Literature review to examine the role of the Internet in informing and supporters of carers of people with cancer 20 published articles were included in the analysis	Carer Internet use can be classified as 'the search for information', 'support group activity' and 'email use'. Carers are often asked to search for information on cancer by patients. Their information and support seeking is not static, but changes according to type, stage and progression of their family members' illness. Interactions in virtual support groups provide information, support and specific information; at the same time, there	The Internet can be a primary or secondary source of information for carers. Relying on it depends on the carer being able to critically appraise the information and process it within the context of their situation. Interactive web-based applications developed specifically for carer use have the potential to prepare, inform and support the carer in their ever-expanding role.

Authors	Study aims and methods	Findings	Implications
		can be conflict between members of these virtual groups that mimics conflicts observed in face-to-face groups.	
Adams, Boulton and Watson (2009)	Systematic review of papers published between 1998 and 2008 assessing the information needs of partners and/or family members of adult cancer patients. 32 papers were included in the review.	The concept of 'information need' was generally poorly developed and theorised in the papers. The information needs of carers differs in scope and perspective from those of patients. A diagnosis of cancer has a significant impact on the partners and family members of patients, and they perceive a need for information on a wide range of topics. A typology of information needs was generated by the researchers. Information needs are contingent on the person's stage in the cancer trajectory.	Future research on carers' information needs would benefit from being more theoretically informed and methodologically robust. Studies should ideally use larger sample sizes, validated measures, and longitudinal, mixed method research designs. Greater attention should be paid to providing information on non-medical supportive care topics to carers. Strategies should be developed to ensure best use is made of available resources, for example signposting by health care professionals to good quality written/web-based information.
Bee, Barnes and Luker (2008)	Systematic review examining the practical information needs of informal caregivers providing home-based palliative and end-of-life care to people with advanced cancer. 26 studies were included in the review.	Studies pointed to a perceived reluctance among health professionals to provide carers with information and guidance relating to incontinence care, dietary control, access to specialist services or equipment, general patient comfort, medication and symptom management. In the absence of adequate information, families typically feel out of control, disempowered to make decisions, and unable to cope with the physical care of relatives. Carers expressed the need to improved information on medication management, greater knowledge of disease progression, increased preparation for the physical demands of caregiving, information on the availability of nursing aids and local resources, and how to perform the non-medicinal elements of caregiving, such as patient nutrition, positioning and bathing. Carers would like greater production of written materials, less reliance on professional 'jargon', increased skills-based training, and more internet support groups, telephone help lines and community college courses.	There is a need for greater rigour in researching this topic. Few of the reviewed studies referenced each other, despite being about the same core research topic. Enhanced access to professional advice can increase carers' confidence to undertake many of the practical aspects of home-based care. Health providers can support home-based carers by providing the information and skills-training necessary to facilitate this. Initiatives should be directed at increasing the awareness that nurses have of carers, improving provider-carer communication, and increasing providers' incentives to work with carers. Carers should ideally be involved in the design and evaluation of educational and information-sharing interventions that can provide them with fit for purpose information and skills training.

4.3 Directions for future research

Research on carers’ information needs and on information-provision to carers would benefit from being more theoretically informed and methodologically robust. This includes having a more developed and theoretically sound concept of ‘information need’ (Adams et al. 2009); adopting exploratory and qualitative research designs that would help to better understand the information needs of carers (Washington et al. 2011); evaluation research using mixed methods in order to test for the effectiveness of information-provision interventions (Thomas et al. 2017); and ensuring that all studies are grounded in a thorough literature review (Bee et al. 2008).

A stronger research agenda would help in particular to address the identified gaps in the literature in respect of understanding Aboriginal and Torres Strait Islander carers; or studies that provide formal evaluation of programs, services and resources for Aboriginal and Torres Strait Islander carers in Australia (Taylor 2013).

In light of the finding that the information needs of carers differ in scope and perspective from those of the persons being cared for (Greenwood et al. 2010), future studies could explore the ways in which service providers may be able to effectively scope, put into practice and assess an information-provision system suited that would meet the needs of all three parties – professionals, carers and the people being cared for. The comprehensive typology of the needs of carers of cancer patients developed by Adams et al. (2009), based on a systematic review of studies (see Table 5 of this report), provides an example that could be applied in research and refined.

In keeping with this focus on the use of frameworks that have been generated in previous research, the classification framework for the ‘level of awareness’ of young carers (Leu and Becker 2017) can fruitfully applied in future research, not only with young carers, but with carers as a whole. It suggests that research on community awareness of carers as a whole or specific caring groups in any jurisdiction can take into account indicators and outcomes relating to:

- awareness within all levels of government
- awareness within society
- sustained policies focusing on carers
- legal acknowledgement and legal rights
- the quality of the research base
- dedicated services and interventions.

5 Carer engagement

5.1 Issues and debates

Fine (2012: 64) identified a key feature of caring in the modern world: it is no longer seen in dichotomous terms. Formal and informal care have become complementary and intertwined. Focusing on care for people with mental illness, for example, Rowe (2012) points out that deinstitutionalisation, healthcare reforms and moves to community care have all contributed to shifting the care of people with severe mental illnesses from hospitals to the community, and specifically to families. When episodes of severe illness make it difficult for carers to cope, hospitalisation and residential care can be accessed. The complementarity of informal and formal care necessitates a working partnership between carers, the people they care for, and service providers.

This requires service providers to engage with carers, both those that self-identify as carers as well as those that are ‘hidden’ carers. There are several aspects to understanding the partnership that develops between formal service providers and informal carers (Wallcraft, Amering, Freiden et al. 2011: 230):

- **Forms and levels of partnership** range from simply providing information to carers, to strongly consumer- and carer-directed models of community-based care.
- **Sites of partnership** range from personal care at the basic level through to strategic networking in organisations and care systems.
- There is a wide **spectrum of collaborative work**: service provision, planning, advocacy, training and education, and research and evaluation.

Service providers tend to adopt one of four models in their response to carers:

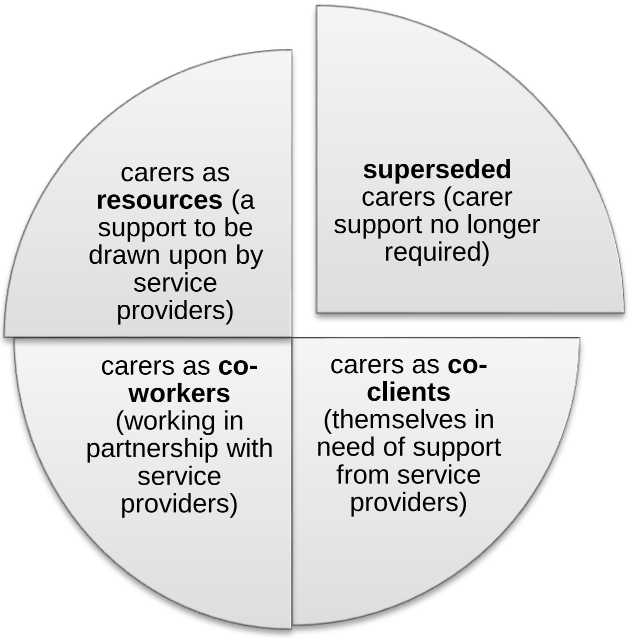


Figure 5: Service providers’ models of working with carers

Source: based on Twigg and Atkin (cited in Milne and Larkin 2015: 7; and in Hill et al. 2016: 17-18)

Organisational practice or ‘culture’, as well as the nature of the caring situation, is likely to influence which model is adopted. In respect of chronic health conditions, for example, carer engagement is ‘often seen as an extension of patient involvement in health care’ (Morrow and Nicholson 2016: 299). From the perspective of GPs, there is value in organising medical practices in such a way that carers can ‘contribute to patient care and be supported in their role’ (Simon 2011: 443). When this is the case, key issues to address include patient confidentiality, information sharing and carer training; making access to health care as easy as possible for carers, in recognition that they often neglect their own health maintenance; being aware of the information and support available from a variety of statutory and voluntary sector organisations, and making appropriate referrals; appointing a carers’ leader within the team to source information and co-ordinate the team effort; and auditing practice performance (Simon 2011: 449).

A model for the engagement of carers of family members with mental illness (Mind Australia 2017) provides an example of a process that can be applied to individual caring situations, evaluated and refined:

- **Identify and welcome** carers and other family members who form part of the client's informal care support system
- **Disseminate general information about services** – information needs to be available routinely, frequently and in different ways
- **Build and maintain communication and relationships** – carers need to know when and how to communicate with staff
- **Involve** carers in service delivery and review
- **Support** carers and family members in their caring roles.

In addition to being partners in care in respect of individual patients or clients, carers are also partners in policy and strategic planning processes. They engage with service providers and policy makers at structural and systemic levels. The Coalition of Carers (Scotland) (n.d.) has put forward a set of three standards for the engagement of carers in strategic planning groups:

carer engagement is fully resourced

- To ensure carers are able to give of their best they need training, induction, mentoring and support.
- Normal expenses such as travel need to be reimbursed.
- The costs need to be met for any substitute/respite care that carers require.

carers who take part in strategic planning groups represent the views of local carers

- Carers will be integrated into a strong network of carers from different caring backgrounds
- Other partners on the strategic planning groups should know with confidence that they are learning of the views of a range of carers

avoid tokenstic involvement of carers

- Carers should be accepted as equal and expert partners

Figure 6: Standards for carer engagement in strategic planning

Source: based on Carers Coalition Scotland (2017)

5.2 Evidence

Studies identified in the literature review that provide evidence for engaging carers as partners in care and in decision-making are summarised in this Chapter's table of evidence (Table 7). Key findings from these studies are discussed next.

On the basis of a scoping review on carers 'perspectives regarding the division of care responsibilities among citizens, government and professionals, Wittenberg et al (2018) generated three themes:

- **Division of responsibilities**: carers view care management and transferring information among various stakeholders about the care situation as their prime responsibility. Carers do not always know what professionals expect of them and often assume they have more involvement in caregiving than professionals think they have.
- **Negotiating the boundaries of the caring role**: the findings underline the importance of professional recognition of the carer's role

- **Collaboration**: the context in which this takes place is important. When the expertise of the carer is acknowledged and the division of responsibilities is clear, collaboration is successful. Obstacles include inflexible structures of provision and poor communication.

As part of a broader study focusing on improving health care for patients with learning disabilities in the UK, Tuffrey-Wijne, Giatras, Goulding et al. (2013) found benefits when service providers developed a sound understanding of barriers and enablers towards involving carers as partners in care. The framework these researchers put forward addresses **cross-organisational** and **organisational** issues, **staffing (individual and team)** issues and **enablers and barriers** arising from the specific situations of carers and persons being cared for. The researchers found that the most important factor contributing to the effectiveness of carer involvement was the degree to which staff identified carer expertise – not only the work that carers accomplished – and welcomed it; and the degree to which the roles of both staff and carers were clarified on an individual basis (Tuffrey-Wijne et al. 2013).

Carer engagement is particularly important when service systems adopt models such as Consumer-Directed Care (CDC) (Cash, Moyle and O'Dwyer 2017), place an emphasis on 'continuity of care' (Wong-Cornall et al. 2017) and/or adopt a clinical case management approach (Corvol et al. 2017). For example, Wong-Cornall et al. (2017) conducted research among Maori carers in New Zealand. The study found that:

- A solid relationship between the carer and the service provider was found to be essential to the relationship between provider and patient within a 'continuity of care' approach to health service delivery.
- Carers actively supported the transfer of health information from one provider to another and from one health care event to another.
- Tasks performed by family carers that improved the integration of services included maintaining treatments plans, scheduling services and appointments, and liaising between health, community and social agencies.
- Carers in this case study were clear that case management was a central component of their role. They sought to build formal partnerships with providers who supported them to achieve their caregiving goals.

The researchers concluded that adopting a 'continuity of care' model shows promise of successfully engaging carers as partners in caregiving and decision-making (Wong-Cornall et al. 2017).

Case management can be described as a 'targeted, community-based and pro-active approach to care that involves case-finding, assessment, care planning, and care coordination…[and it]…always involves both the patient and the caregivers' (Corvol et al. 2017: e1). These researchers studied the full range of consequences of clinical case management for caregivers of frail older persons or persons with dementia (see Table 3) and found that it can lead to positive outcomes for carers, as well as positive outcomes for frail older patients without increasing caregiver burden.

Engagement may also be important for service providers when they recognise that a segment of the caring population is being under-served and where forms of 'outreach' are called for in order to address these service gaps. For example, on the basis of research carried out in the UK, Moriarty, Manthorpe and Cornes (2015) suggest that organisations providing support for carers need to consider the advantages and disadvantages of different models of outreach as they develop carers' support initiatives. Providers should consider the extent to which different models might be more effective than others in reaching particular types of carer, and be aware of sensitive issues facing particular groups of carers, such as those who may be stigmatised or discriminated against.

5.2.1 Engaging specific groups of carers

Prominent in the literature on carer engagement is research focusing on carers of people with mental illness. As McMahon and Hardy (2010) point out, the identification and engagement of carers is crucial in any recovery-based approach to mental health care. Rowe (2012) writes that caring for a relative with severe mental illness is a distinct and unique experience that few people are adequately prepared for. Possibly complicating factors that need to be considered include (McMahon and Hardy 2010):

- Some carers who self-identify as such are not necessarily the best people to be involved in the ongoing care and recovery of mental health consumers, either because of their past history with the consumer, or their own particular needs.
- While the ideal process for identification is by the consumer, some consumers may refuse to identify or to involve carers.
- No single clinician or carer can meet all the needs of all consumers.

Wallcraft et al. (2011) report on the World Psychiatric Association's (WPA) *Taskforce on Best Practice in Working with Service Users and Carers*, which suggests that there is strong support for adoption of participation principles such as:

- respecting human rights as the basis for successful partnerships in mental health
- collaborative development of legislation, policy and clinical practice relevant to the lives and to the caregiving of people with mental illness
- support for both users' and carers' organisations, recognising also there may be challenges in determining which organisations should be supported, and which not
- recognising that clinical care, education, research and quality improvement in mental health care all require collaboration between users, carers and service providers.

Based on qualitative research carried out in the UK on carer involvement in shared decision-making in the context of mental illness, Bradley and Green (2018) found that it was essential to make explicit the 'rules of engagement' for family input. In addition, awareness of the barriers and of policies (including patient confidentiality policies); and disseminating the potential benefits of family input are important first steps to encourage staff to consider family involvement as a core constituent of shared decision-making. Issues to keep in mind include: some carers believed that staff perceived them in a negative light and were actively excluding them; and some staff felt challenged by family members who held different – possibly antagonistic – views about what would be in the best interests of the patient (Bradley and Green 2018).

There is strong support for mental health service providers to acquire new skills, undergo a culture shift and integrate the values of carer involvement into their daily practice (Tambuyzer and van Audenhove 2013). McMahon and Hardy (2010) support the view that a 'partnership and recovery' approach to mental health care will improve consumer outcomes and decrease the burden on both service providers and informal carers. In Scotland, the legislative establishment of the 'Named Persons' role (the service user nominated the person they wanted to help protect their interests in the event of compulsory measures being taken) and Mental Health Tribunals were found to be promising steps forward in ensuring that family carers of people with mental health problems were acknowledged and engaged (Ridley, Hunter and Rosengard 2010).

In connection with cancer care, Hubbard et al. (2010) found that the flow of information between clinicians and the patient and carer dyad is an important facet of the treatment decision-making process. The informational role of the carer can be conceptualised as the carer functioning as **conduit** in processing the information given by service providers; and carers serving as **sound-boards** for the patient able to stimulate thinking about treatment decisions and processes behind the scenes. These researchers also identify that the role of the carer during information exchange was dependent on factors including:

- whether the patient was able to process the information provided
- the carer's ability to pre-empt patient information needs
- both the carer's and the patient's perceptions about whether or not different treatment options were available (Hubbard et al. 2010).

Miller, Whitlatch and Lyons (2016) carried out a systematic review of the empirical literature on decision making within the context of dementia care and found that there is a broad spectrum of what constitutes shared decision-making in dementia. The focus of decisions included those relating to everyday care, medical treatment, and long-term care placement. Carers' perceptions of the ability of the person with dementia to participate in decision-making was an important factor in their own involvement in decision-making; and when carers believed that the persons with dementia are more involved in decisions, they themselves have better quality of life and less depression, and experience reduced carer burden (Miller et al. 2016).

Based on an analysis of studies published between 1990 and 2015, Morrow and Nicholson (2016) identified six integrated components of effective carer engagement in the context of the care of older people in hospital settings, illustrated in Figure 7:

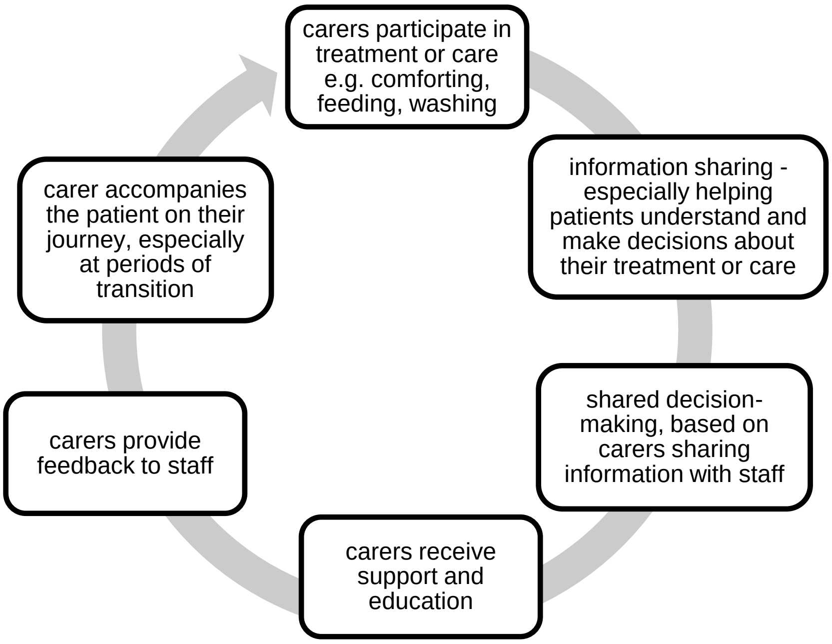


Figure 7: Components of carer engagement focusing on older people

Source: based on Morrow and Nicholson (2016)

This model, which provides a good example of the intersection between formal and informal care (as discussed earlier) may be developed and extended to other groups of carers as well.

5.2.2 Engaging Aboriginal and Torres Strait Islander Carers

As part of the *Carers and Social Inclusion: New Frameworks, Evidence and Policy Lessons* project led by the Social Policy Research Centre at the University of New South Wales (UNSW), Raven (2016) conducted a series of 'yarning circles' with Aboriginal carers, which yielded valuable qualitative data. These data suggest that Aboriginal carers would benefit from:

- explicit acknowledgement of their human rights
- ongoing funding for Aboriginal carer support groups and services
- support being provided to carer advocates
- assistance in carrying out caregiving functions, such as household chores
- access to information about changes to policies, services and funding such as the National Disability Insurance Scheme (NDIS).

Raven (2016) highlights the point raised by other researchers as well that Aboriginal and Torres Strait Islander carers do not always recognise themselves as 'carers'. Instead, they view the caregiving that they carry out as a given aspect of normal kinship roles. Focusing on Aboriginal carers of children with disability, Green et al (2018) found a perception of being looked down upon and judged by mainstream providers and, in addition, their experience of poverty and homelessness challenged their ability to access care. The authors suggest that the following can be useful in breaking down barriers to care:

- Community-led models of care
- Increasing cultural competence in mainstream services
- Appreciating the complex ways in which carers experience and make meaning of their interactions with individual providers while accessing care, including past experiences of marginalisation
- Appreciation of the social determinants of health and health care
- Being aware of inherent power differentials between providers and carers.

An aspect of carer engagement is that of recruiting carers within Aboriginal and Torres Strait Islander communities to become foster carers. Higgins and Butler (2007) put forward a process that could be used to help an informal carer move to becoming a registered carer. Culturally-appropriate assessment tools work best when staff:

- Allow time to build engagement and trust
- Use story telling approaches rather than lists of direct questions
- Don’t ask questions when the information has been gathered elsewhere, such as in a training session
- Draw on community knowledge about the potential of a carer/family to provide care
- Assess for the same general competencies as for non-Indigenous carers
- Also assess for active participation in Aboriginal communities; demonstration of an understanding of Aboriginal kinship systems; knowledge of services for Aboriginal children and young people; an understanding of the impact of past welfare practices on Aboriginal people.

An important finding from the consultations undertaken by these researchers was the overlapping nature of recruitment, assessment, training and support programs for carers on the one hand, and services for enhancing outcomes for carers, children and young people on the other (Higgins and Butler 2007).

The table of evidence summarising the key studies focusing on engaging carers as partners in care and decision-making (Table 7) follows next.

Table 7: Table of evidence: Engaging carers as partners in care and decision-making

Authors	Study aims and methods	Findings	Implications
Wittenberg et al. (2018)	Scoping literature review on the views of informal carers regarding the division of care responsibilities between citizens, government and professionals 13 studies were included in the qualitative synthesis	Three themes can be generated from the literature: • **Division of responsibilities**: carers view care management and transferring information among various stakeholders about the care situation as their prime responsibility. Carers do not always know what professionals expect from them and often assume they have more involvement in caregiving than professionals think they have. • **Negotiating the boundaries of the caring role**: the findings underline the importance of professional recognition of the carer's role • **Collaboration**: context is important. When the expertise of the carer is acknowledged and the division of responsibilities is clear, collaboration is successful. Obstacles include inflexible structures of provision and poor communication.	Working with and supporting carers may not always be foremost in the minds of professional helpers, but this should change. Educational programs in social work and the health and allied health professions should place greater emphasis on this specific characteristic of partnership working. Research should focus on expanding knowledge about the possible differences in staff and carers' views on the division of care responsibilities, aiming for insight into the values/ideals which may shape these views. Qualitative research is called for in this regard.
Bradley and Green (2018)	Qualitative research carried out in the UK The aim was to better understand how family carers of adults diagnosed with severe mental illness are involved in decision making and to identify barriers and facilitators for engaging them in decisions about treatment. Open-ended questions were sent to staff (N=55) and carers (N=46) to elicit written responses. Qualitative responses were analysed thematically.	Staff value the contextual information that family can provide, particularly at points of decision making. Despite this, family felt the information they shared with teams remained on the periphery of decision making. Family and staff ascribe practical, rather than recovery-oriented roles to family members, with pre-occupation around notions of adherence. Making explicit the 'rules of engagement' for family input, heightening awareness of the barriers, increasing awareness of policy (including patient confidentiality policies) and disseminating the potential benefits of family input would be important first steps to encourage staff to further consider family involvement as a core constituent of shared decision-making.	The researchers put forward a model on 'Rules of Engagement' as a basis for future research. Themes within the model are: 1. Navigating patient permission as the first step 2. Actively encouraging carers' attendance at appointments by sharing information or negotiating meeting times. 3. Information exchange – important role played by family in providing wider, contextual information about the service user, to enhance understanding and inform decision making 4. Monitoring – involve carers in decision making because of their monitoring and motivating roles with clients

Authors	Study aims and methods	Findings	Implications
			5. Negotiating staff permission and the carer's agenda – sense from some family participants that staff perceived them in a negative light and actively excluded them; some staff felt challenged by family members who held different, and possibly antagonistic, views
Cash, Moyle and O'Dwyer (2017)	An integrative review of the literature on relationships between community aged care recipients, family carers and care providers under consumer-directed care (CDC) Literature published between 1998 and 2014 was included. 15 studies met the inclusion criteria	In all countries and contexts, good relationships are key to successfully undertaking and negotiating CDC. This includes the relationships between family and care recipients; as well as the relationship between the service provider and the caring dyad (care recipient and family). Forming a care plan opens a dialogue between the care recipient and family carer around issues such as care preferences and goals and aspirations that may have previously been missing. By promoting the active contribution of the care recipient, it may be that care outcomes can be improved.	There has been limited research into issues surrounding caregiving relationships and CDC. In particular, this review found no research with a particular focus on older adults or those with dementia – this is concerning in light of recent figures estimating that, in Australia, one in 10 people over 65 years and three in 10 people over 85 receiving community aged care have dementia. This is a priority for future research.
Wong-Cornall et al. (2017)	The study, based in New Zealand, explored the contribution of family carers to the provision of care and support for an older family member's chronic condition within a 'continuity of care' approach to health service delivery. Interviews were held with 13 purposefully sampled family carers in a Maori service.	There was alignment of family caregiving roles and functions with the three levels of continuity of care (relational continuity of care, informational continuity of care, and management continuity). In particular: • A solid relationship between the carer and the service provider was key to a good provider-patient relationship. • Carers actively supported the transfer of health information from one provider to another and from one health care event to another. • Tasks performed by family carers that improved the integration of services included maintaining treatments plans, scheduling services and appointments, and liaising between health, community and social agencies.	Explicitly adopting a 'continuity of care' model shows promise of successfully engaging carers as partners in caregiving and decision-making. Within this model, case management is a central component of their role. They sought to build formal partnerships with providers who supported them to achieve their caregiving goals. Relationships between service providers and the family unit inclusive of the patient and family carer are crucial for establishing good long-term care. Future studies should assess the level of relational engagement between family carers and providers, and the impact of carer-provider partnerships on informational and management continuity with the aim to move away from a 'reactive culture' in health services.
Morrow and Nicholson (2016)	Integrative literature review exploring the concept of carer	Six distinct components of carer engagement were identified:	An integrated model of carer engagement is put forward (see Figure 6 earlier in this report). Future research

Authors	Study aims and methods	Findings	Implications
	engagement in the care of older people in hospital settings Peer reviewed studies published between 1990 and 2015 were considered; 103 articles were included	• Patient caregiving – carers participate in patients' treatment or care (e.g. comforting, feeding or washing) • Information sharing – carers help patients to understand and make decisions about their treatment or care • Shared decision-making – carers share information with staff • Carer's receipt of support and education • Carers' feedback to staff about patient care and the experience of caring • Carers supporting patients on their care journeys, especially the transitions.	could test the integrated model with carers of different age, gender and ethnicity. Developing carer engagement is not only about freeing up staff time in busy hospital environments, it also concerns developing cultures of care that value and enable carer engagement
Miller, Whitlatch and Lyons (2016)	Systematic review of the empirical literature focusing on carers' and patients' involvement in decision-making processes in the context of dementia. Studies were included that were published in peer-reviewed journals between 1999 and 2014 and had a focus on carers' inclusion in decisions about everyday care, medical care and treatment, or long-term care. 36 studies were included	Carers' involvement in decision-making is often essential to the process of translating the values of the persons with dementia into decisions. There is a broad spectrum of what constitutes shared decision-making in dementia. Types of decisions include those relating to everyday care, medical treatment, and long-term care placement. Carers' perceptions of the ability of the person with dementia to participate in decision-making is an important factor in their own involvement in decision-making. When family carers perceive that persons with dementia are more involved in decisions, they themselves have better quality of life, less depression, and experience reduced carer burden.	Theoretical perspectives support the practice of shared decision-making within the family care dyad. There are models of interventions with outcomes intended to improve the shared decision-making process among family care dyads. Many studies made use of a scale – the Decision Making Involvement Scale – that includes 15 items, and this or similar scales are useful for further research. More research is needed on shared decision-making in family care dyads.
Raven (2016) **Part of the *Carers and Social Inclusion: New***	This report represents findings from 'yarning circles' held in northern Adelaide and Port Augusta.	Participants do not always recognise themselves as 'carers' – caregiving was typically viewed as a given aspect of normal kinship roles. For many carers, caregiving duties took up the bulk of their time. Their roles include advocacy, decision-making,	Aboriginal and Torres Strait Islander carers would benefit from: • their human rights to be respected an upheld

Authors	Study aims and methods	Findings	Implications
***Frameworks, Evidence and Policy Lessons* project (social Policy Research Centre UNSW)**	The aim was to contribute to the generation of indicators for social inclusion for Aboriginal carers.	protecting care receivers from harassment and abuse, transport, and household duties. Caregiving provided rewards, including giving opportunity to pass on and receive cultural knowledge; and challenges, such as needing to leave school or employment to care for relatives, and the stresses of ongoing negotiating with family, service providers and government. Carers often need to travel long distances to access support services.	• ongoing funding for Aboriginal carer support groups and services • the support of carer advocates • assistance in carrying out caregiving functions, such as household chores • access to information about changes to policies, services and funding e.g. the National Disability Insurance Scheme
Moriarty, Manthorpe and Cornes (2015)	Mixed methods study exploring outreach activities by organisations, especially local councils, in respect of carers. Face-to-face semi-structured interviews were undertaken in four different parts of England and email/postal responses to a survey sent to all adult social care directors. thematic analysis	There are varying definitions and different models of outreach work but the underlying aim is to start a process of social interaction between people in need and a support organisation. Outreach should be seen as different from providing information. Hidden carers are unlikely to come forward unless they thought that they would be treated fairly and in accordance with their wishes – for example gay, lesbian, bisexual or transgender carers may have previous experiences of discrimination.	Organisations providing support for carers need to consider the advantages and disadvantages of different models of outreach as they develop carers' support programs, and the extent to which different models might be more effective than others in reaching particular types of carer. Changes to information technology have meant that it is increasingly expected that people will access social and healthcare information online. Debates on this topic are usually framed in terms of the 'digital divide' and differences between those who can use and have access to the Internet, and those who do not.
Tuffrey-Wijne, Giatras, Goulding et al. (2013)	As part of a broader study focusing on improving health care for patients with learning disabilities in the UK, the researchers explored the involvement of carers as partners in care. Methods included a carer questionnaire and staff survey	Involvement of carers within the National Health Service (NHS) in the UK is patchy and unpredictable. The most important factor contributing to the effectiveness of carer involvement was the degree to which staff understood the importance of carer expertise (rather than simply carer work) and welcomed it; and the degree to which the roles of both staff and carers were clarified on an individual basis. Factors contributing to effective carer involvement include protocols for shared care, practical support for carers, an organisational culture where carers are welcomed as a matter of course, and funding for high care needs.	The authors put forward a framework of barriers and enablers towards involving carers are partners in care. The framework addresses: • Cross-organisational issues • Organisational issues • Staff: individuals and teams • Carers and person being cared for. Research, policy and practice should take account of the finding that there may be discrepancies between staff and carer understanding of the carer role.

Authors	Study aims and methods	Findings	Implications
		Focus needs to be placed on situations where staff and carers have different perceptions of the nature of the carer's role.	
Tambuyzer and van Audenhove (2013)	The study, carried out in Belgium, assessed differences between service users', family carers' and mental health care providers' perceptions on service user and family carer involvement in mental healthcare. 111 service users, 73 family carers and 216 mental healthcare providers were included in the study	All stakeholder groups perceive most aspects of involvement as relatively important. Service users and carers hold more favourable views on the importance and the realisation of their involvement than do providers. Carers gave higher ratings than providers on the realisation of a range of aspects regarding their involvement in care meetings. Troubled relationships between service users and carers, practical restrictions (e.g. meetings during working hours) and the social isolation of many service users may hamper the involvement of carers.	Providers need to acquire new skills, undergo a culture shift and integrate the values of carer involvement into their daily practice. Progress can be made through staff training and developing formal involvement procedures. Researchers should focus on developing more rigorous approaches to measuring carer involvement in the lives of people with mental illness. 'Expertise by experience' is a useful approach to integrate the experiences of carers and, indeed, patients, in mental health care.
Rowe (2012)	Systematic review on the role of carers of family members with severe mental illness The focus was on their relationships and engagement with professional staff. The research questions were 1. What do mental health professionals expect family carers to do? 2. What do family carers expect of themselves in terms of their relative?	A total of 13 studies met the inclusion criteria. Of these, 12 used qualitative, and one mixed methodology. Caring for a relative with severe mental illness is a distinct and unique experience that few people are adequately prepared for. Obligations placed on carers by themselves and by mental health professionals included becoming involved in their relative's care, sharing information and assisting in recovery. These obligations may be willingly carried or may be thrust upon carers. In either case, carers are entitled to empathy, respect and recognition for the complex and emotionally challenging job they do. Alongside these obligations, carers also had rights: being acknowledged and respected as a partner in care that enabled the fulfilment of their obligations.	The quality of engagement and communication, and developing and maintaining relationships between professionals and family carers are important means of enhancing the effectiveness of the carer role. This requires changes to professional attitudes and practices and more awareness among carers about mental health issues and their day to day management. Recommendations for professionals include developing skills in empathic communication with carers; explicit inclusion of carers in service provision; and providing carer assessments. All of these require changes to training and professional development.
Wallcraft et al. (2011)	A large-scale international initiative was undertaken to understand and promote	Families are involved in training and education, advocacy, research and evaluation, planning, management, and service provision. It includes a focus on the partnership process, which begins with setting	In addition to the medical focus of care for people with mental illness, attention should be given to supporting the wellbeing of communities and the development of healthier environments.

Authors	Study aims and methods	Findings	Implications
World Psychiatric Association (WPA)*Taskforce on Best Practice in Working with Service Users and Carers*	person-centred practice in mental health care. It included a literature review, consultations, and an online survey focusing on service user and carer involvement in improving mental health.	goals. There is strong support for adoption of participation principles such as: • Respecting human rights is the basis of successful partnerships for mental health. • Legislation, policy and clinical practice relevant to the lives and care of people with mental disorders need to be developed in collaboration with users and carers • Support for both users' and carers' organisations is important, although there are challenges in determining which organisations should be supported, and which not. • Clinical care, education, research and quality improvement in mental health care all require collaboration between users, carers and service providers. Barriers to partnership emerge repeatedly in the literature. These include: • lack of clarity on commonly used terms such as 'representativeness' and 'accountability' • lack of support and training for the stakeholders • 'tokenistic' approaches to partnership.	In order to generate valid and reliable evidence for better practice, research needs to recognise that mental health care situations vary dramatically across countries and cultures; and that service users and family members may have different agendas.
McMahon and Hardy (2010) **Identifying the Carer Project** **Funded by the Australian Government Department of Health and Ageing**	The project was undertaken to examine issues associated with the identification of carers of people with mental illness which could help to determine their information needs at the time of admission of a family member to a service. Consultations were undertaken nationally by way of focus groups with carers; individual meetings with key	All study participants believed that identification and engagement of carers is crucial in any recovery based approach to care. At the same time, health services continue to make little effort to identify or involve carers. Many respondents felt that the majority of clinicians did not seem to know how to go about this process. Identification is not a one-off process. Policies and protocols to identify carers are essential and will vary according to service setting. Complicating factors that need to be considered include:	A partnership and recovery approach to care will improve consumer outcomes and decrease the burden on both service providers and informal carers. A nationally consistent information brochure for families and other carers is highly desirable as it will improve mental health carer literacy and opportunities for engagement. The researchers put forward a carer identification and engagement good practice checklist for staff, with the recommendation that it be adopted nationally by public and private services.

Authors	Study aims and methods	Findings	Implications
	stakeholders – a total of 97 participants were included. A literature review was also completed.	• Some carers who self-identify are not necessarily the best people to be involved in the ongoing care and recovery of consumers, either because of their past history with the consumer, or their own particular needs. • While the ideal process for identification is by the consumer, some consumers may refuse to identify or to involve carers. • No single clinician or carer can meet all the needs of all consumers.	There is value in having a specific member of staff with responsibility for maintaining procedures for identification of carers – a carer ‘specialist’ or ‘champion’. There is value in having ‘carer corners’ in waiting rooms.
Hubbard et al. (2010)	The study explored the role of the carer in treatment decision-making in cancer care A qualitative and longitudinal research design was adopted, with three serial semi-structured interviews with 66 patients and 43 carers within the first year following a diagnosis of cancer	The flow of information between clinicians and the patient and carer dyad is important in the treatment decision-making process. The informational role of the carer can be conceptualised as: • Carer as conduit in processing the information given by service providers • Carers as sound-boards for the patient able to stimulate thinking about treatment decisions and processes behind the scenes.	Models of cancer care practice that fail to acknowledge the role of the carer in the treatment decision-making process are deficient. Practice could be enhanced by the inclusion of the carer in conceptual frameworks and recommend triadic (patient, carer and professional) models of practice.
Ridley, Hunter and Rosengard (2010)	A cohort study was carried out with a group of carers (N=33) following implementation of the *Mental Health (Care and Treatment) Act Scotland 2003* The study explored carers’ views on the legislative changes, especially as regards the goal to enhance carer involvement. Qualitative data were gathered by means of focus groups and interviews.	Carers who participated in the study rarely labelled themselves as such. Despite new legislative provisions, many carers felt isolated and were ambivalent about the value of professional assessments of their needs. Carers wanted to be consulted more often by health and social services, and to be involved at both individual and collective levels. The demands of the caring role are strongly affected by the fluctuating nature of mental health problems. Carers reported that establishment of the ‘Named Persons’ role (the service user nominated the person they wanted to help protect their interests in the event of compulsory measures being taken) and Mental Health Tribunals were promising steps forward.	Carers of people with mental illness need to be recognised and embedded within the workings of the mental health system. Key to overcoming the barriers to effective care is the quality of engagement and communication between professionals and family carers. It requires changes to professional attitudes and practices and more awareness among carers about mental health issues and their day to day management. An important policy goal would be to treat carers as ‘experts’ in their own right; to support carers to care, as well as supporting them to have a life outside of caring; and to recognise that carers are not a homogenous group.

Authors	Study aims and methods	Findings	Implications
Higgins and Butler (2007)	The study aimed to discover best practice in recruiting and engaging Aboriginal carers. The first phase involved identifying strengths and barriers; the second phase profiled promising programs. Findings were presented in booklets, widely distributed through the Australian Institute of Family Studies.	An important finding from the consultations was the overlapping nature of recruitment, assessment, training and support programs and services for enhancing outcomes for carers, children and young people. Successful strategies included: • incorporating community knowledge about a family when making assessments about whether a potential carer has the qualities necessary to provide appropriate care • using Aboriginal and Torres Strait Islander organisations to recruit Indigenous carers • using experienced Indigenous carers to speak at recruitment information sessions • building a relationship with carers over the long term	The researchers put forward a process that could be used to help an informal carer move to becoming a registered carer. Culturally-appropriate assessment tools work best when staff: • allow time to build engagement and trust • use story telling rather than administering lists of direct questions • don’t ask questions when the information has been gathered elsewhere (e.g., a training session; informal communication with potential carer) • draw on community knowledge about the potential of a carer/family to provide care • assess for the same general competencies as for non-Indigenous carers • also assess for active participation in their communities; demonstration of an understanding of Aboriginal kinship systems; knowledge of services for Aboriginal children and young people; an understanding of the impact of past welfare practices on Aboriginal people

5.3 Directions for future research

Gaps in the current evidence base suggest the need for research that examines and evaluates models of carer engagement in the context of consumer-directed models of care. With respect to dementia care in the community, this need is urgent (Cash et al. 2017). Studies would benefit from making use of engagement frameworks already available in the literature (e.g. Morrow and Nicholson 2016; Mind Australia 2017; Miller et al. 2016) and refining them.

An implication for practice and research is the insight provided by Wittenberg et al. (2018) that working with and supporting carers may not always be foremost in the minds of professional helpers. In keeping with this insight, Wong-Cornall et al. (2017) call for studies that examine the impact of carer-provider partnerships on informational and management continuity within the health services. This includes a stronger focus on the outcomes of case management on both carers and patients (see Corvol et al. 2017).

The research conducted by Tuffrey-Wijne et al. (2013) has generated a framework of barriers and enablers towards involving carers as partners in care. It suggests that future research could focus holistically or individually on examining the impact of cross-organisational issues; organisational issues; the professional providers; and the skills, attitudes and knowledge of carers.

Tambuyzer and van Audenhove (2013) argue that researchers should develop more rigorous approaches to measuring carer involvement in the lives of people with mental illness. This suggests that there are gaps in understanding how best family members can provide care, also taking into account the episodic nature of many mental illnesses. Since, as Rowe (2012) has found, the quality of engagement and communication between professionals and family carers is important to enhance the effectiveness of the carer role, it requires research designs that will shed light on the development of these relationships over time. Research could focus on, amongst others, the impact of skills development aiming to improve providers' empathic communication with carers; explicit inclusion of carers in service provision; and providing carer assessments. Navigating professional concerns about patient confidentiality (Bradley and Green 2018) is also an important area to explore.

Moriarty et al. (2015) have shown that there is value in carrying out and evaluating carer outreach programs, on the assumption that many carers are under-served, and also recognising that many carers do not identify as carers.

6 Evidence to shape policy and programs

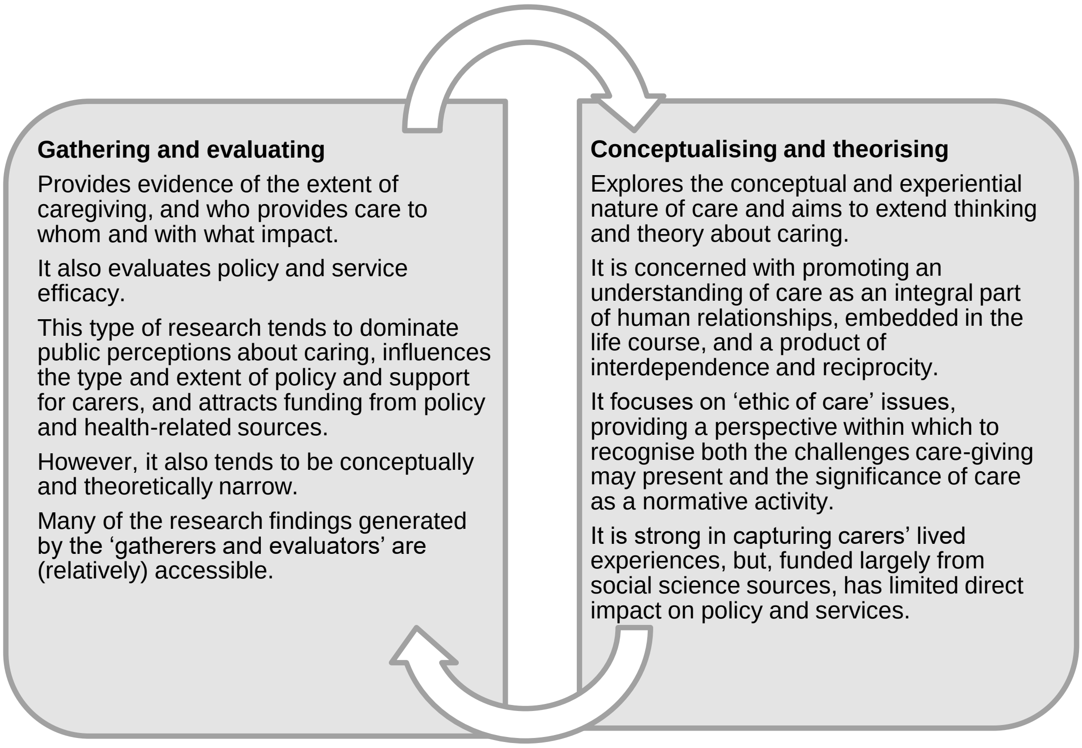
6.1 Taking stock of carer-related research

Both in Australia and internationally, research on carers is dynamic and extensive. As summarised by Thomas et al. (2017: xxi):

> *Policy and research interest in carers – those who provide support, on an unpaid basis, to ill, disabled or older people to enable them to live in their own homes – has grown in importance over the past 30 years… the national and international body of research literature has grown substantially.*

The conduct and the outcomes of this literature review support this contention.

Milne and Larkin (2015) identify two largely separate bodies of carer-related research, the one they label ‘gathering and evaluating’ and the other ‘conceptualising and theorising’:



Gathering and evaluating

Provides evidence of the extent of caregiving, and who provides care to whom and with what impact.

It also evaluates policy and service efficacy.

This type of research tends to dominate public perceptions about caring, influences the type and extent of policy and support for carers, and attracts funding from policy and health-related sources.

However, it also tends to be conceptually and theoretically narrow.

Many of the research findings generated by the ‘gatherers and evaluators’ are (relatively) accessible.

Conceptualising and theorising

Explores the conceptual and experiential nature of care and aims to extend thinking and theory about caring.

It is concerned with promoting an understanding of care as an integral part of human relationships, embedded in the life course, and a product of interdependence and reciprocity.

It focuses on ‘ethic of care’ issues, providing a perspective within which to recognise both the challenges care-giving may present and the significance of care as a normative activity.

It is strong in capturing carers’ lived experiences, but, funded largely from social science sources, has limited direct impact on policy and services.

Figure 8: Towards greater integration of the two bodies of carer-related research

Source: based on Milne and Larkin (2015)

Milne and Larkin (2015: 11) hold that ‘much could be gained for citizens, carers and families, and the generation of knowledge advanced, if the two bodies of research were integrated to a greater degree’.

A clear finding from this review of the literature is the strength of the empirical research focusing on carer health and wellbeing and the provision of supports to carers – this topic, perhaps more than the other priority topics, lends itself to research designs that test for the effectiveness of interventions using robust research designs. Research that examines the effectiveness of interventions to promote carer health and wellbeing – as well as all of the other priority areas discussed in this report – can be graded on the basis of the level of evidence it provides. A model for the grading of evidence is provided by Hudson et al. (2010: 2), is summarised in Table 8.

Table 8: Levels of evidence based on research design

Level	Research design	Enhanced grading
Grade I – Strong evidence	Randomised Controlled Trials (RCTs) Systematic review of RCTs	IA – Calculation of sample size; accurate standard definition of appropriate outcome variables IB – Accurate and standard definition of appropriate outcome variables IC – Neither of the above
Grade II – Fairly strong evidence	Prospective study with a comparison group. Includes: • non-randomised controlled trial or quasi-experiment • good observational study • retrospective study that controls effectively for confounding variables	IIA – Calculation of sample size; accurate, standard definition of appropriate outcome variables; adjustment for the effects of important confounding variables IIB – One or more of the above
Grade III – Weaker evidence	Retrospective or observational studies	IIIA – Comparison group, calculation of sample size, accurate and standard definition of appropriate outcome variables IIIB – Two or more of the above IIIC – None of these
Grade IV – Weak evidence	Cross-sectional study Delphi exercise Consensus of experts	

Source: Hudson et al. (2010: 2)

There are significant methodological challenges to conducting studies that generate strong or fairly strong evidence (Williams and Owen 2009). While RCTs are the ‘gold standard’ of evidence-based research, they are costly and require skilled designs in order to ensure they reliably measure intervention and outcome variables within the complexity of caring and service-provision. Many researchers (see e.g. Hubbard et al. 2010; Ridley et al. 2010; Moen and DePasquale 2017) point to the value of qualitative research, particularly as a means of understanding this complexity, and to gain greater insights into carers’ changing needs and emotions.

On the basis of a stocktake on current research into care and caring, Moen and DePasquale (2017) put forward a policy-relevant research agenda that includes:

- Supplementing the dominant medical approach to research with approaches that also rigorously investigate context, processes and mechanisms of change
- Comparative cross-cultural, cross-cohort and cross-national analysis that includes a wide range of variables
- Documenting social heterogeneity, vulnerability and inequality within carer cohorts
- Capturing individuals’ and families’ adaptive strategies and cycles of control during the caregiving processes
- Investigating policy innovations and natural experiments which achieve much of the power of RCTs without deliberate assignment to experimental and control groups by the researcher
- Assessing the role and activities of third parties – families, social networks and community organisations – as mediators that help to buffer carers from stress and alleviate carer burden
- Attending to subjective meanings of care.

6.2 Strengthening research impact on the lives of carers

In this Chapter, examples are provided of approaches that, it is argued, enhance the impact of research on the lives of carers. Three broad strategies are discussed:

- Operating a carer-specific online database
- Synthesising the research evidence and writing it up in a way that is accessible in terms of language and approach
- Making information available in edited form on a carer organisation’s website

6.2.1 Carer-specific database

The example of CAREN, the Carer Research and Knowledge Exchange Network, based at the Open University in the UK, is briefly summarised in this sub-section as a case study of making research publicly available.

CAREN is a freely accessible knowledge exchange resource for governments, carers, employers, policy makers, practitioners, researchers, NGOs and research funders around the world who require any form of carer-related knowledge. Examples of CAREN’s key roles are provision of information and evidence to support decision-making and cost-effectiveness in decision-making both by carers and practitioners, dissemination and facilitation of dialogues between carers, researchers, PhD students, research funders, policymakers and practitioners, and acting as a source of information about policy consultations and policy development for carers, government departments and NGOs/third sector organisations.

The vast body of research that CAREN catalogues (see http://wels.open.ac.uk/research-project/caren/) accessible online. Searching for material is facilitated through the listing of the resources according to 62 themes which are organised into four clusters (Figure 9):

Carer variables

- Adult children
- Carer characteristics
- Caring at a distance
- Cultural factors
- Ethnicity
- Expert carers
- Friends, neighbours and siblings
- Gender and care
- Hidden carers
- LGBT
- Older carers
- Projections of carer supply
- Relationships and care
- Rural issues
- Sandwich carers
- Spouse care
- Young carers

Impact of care

- Abuse and care
- Bereavement
- Burden of care
- Care costs
- Carer depression
- Carers and employment
- Carers and health
- Carers needs
- Conflict in caring
- Crisis
- Entering residential care
- Ethical issues in caring
- Individual impacts of caring
- Longitudinal study
- Measuring and evaluation
- Post-caring
- Psychological impact
- Quality of life
- Resilience and coping
- Risks in care
- Satisfaction and caring
- Social exclusion
- Stress and strain
- The lifecycle and care

Support and carers

- Assessment
- Care Act 2014 (UK) evaluation
- Carer support
- Cash for care
- Professional education
- Respite
- Social support and networks
- Technology and telecare
- Training and carers
- Value of care

Type of care

- AIDS/HIV
- Cancer
- Caring for older people
- Complex needs
- Dementia
- End of life
- Learning disability
- Long term conditions
- Mental health
- Nature of care
- Stroke survivors

Figure 9: Carer themes and topics in the CAREN research resources

This categorisation of carer research themes is useful of itself as a way to make sense of the breadth of the field. It is noteworthy that the ‘impact of care’ cluster contains the largest number of themes. A clear benefit of having a carer-specific database of this nature is that it is regularly updated. On the other hand, the material, often of a professional nature, is accessible only in the way it is published, which may be daunting for many carers.

A similar approach has been adopted by CarersNSW, who provide ‘research snapshots’ made available online (see e.g. https://www.carersnsw.org.au/Assets/Files/47%20Jan%2017.pdf).

6.2.2 Accessible synthesis of the evidence-base

Williams and Owen (2009) provide a good practice example of applying a literature review approach to analysing material generated through empirical research and presenting it in a way that can benefit carers directly (through reading it themselves) and indirectly (through it being made available to service providers and policy makers). These authors drew on the research report delivered in connection with the study (Effective caring: A synthesis of the international evidence on carer needs and interventions) to write a shortened, more accessible text published by the Australian Institute of Family Studies and made available online. The writing provides useful summaries of:

- the strength of evidence on interventions, based on five levels, similar to the approach adopted by Hudson et al. (2010), outlined in Table 8 above, but in more accessible language
- types of evidence, including profiles of carer populations and carer’s views
- what works to help carers, with qualifications of the support for effectiveness drawing on the literature sources.

One requirement of this approach is to have personnel with the skills and resourcing to synthesise literature in both a rigorous and accessible, layperson-friendly way.

6.2.3 Online information

Adams et al. (2009) concluded on the basis of a systematic review that strategies are needed to ensure that the best use possible is made of available resources. One suggestion is signposting carried out by health professionals to good quality web-based information.

Another approach is to draw on research and scholarship to ‘repackage’ information and evidence in a way that is highly accessible in terms of language and finely targeted to the needs of carers. Dementia Australia provides an example of a carer-focused NGO making assigning part of its website for these ends. Its ‘Information and ideas for carers, family members, and friends’ pages (https://www.dementia.org.au/information/about-you/i-am-a-carer-family-member-or-friend) take information from studies focusing on topics such as ‘sleeping’ and ‘personal care’ and summarise it for the target audience – carers themselves. Sometimes the source of the information is referenced.

The success of this approach relies on having staff with the skills and briefs to translate often difficult terminology and concepts into approachable language; and strong quality control to ensure that the material that is drawn upon and presented to carers is trustworthy and evidence-based.

6.3 Involving carers in research

According to Repper, Simpson and Grimshaw (2014), carers can contribute to the development of the evidence base and practice in the following ways:

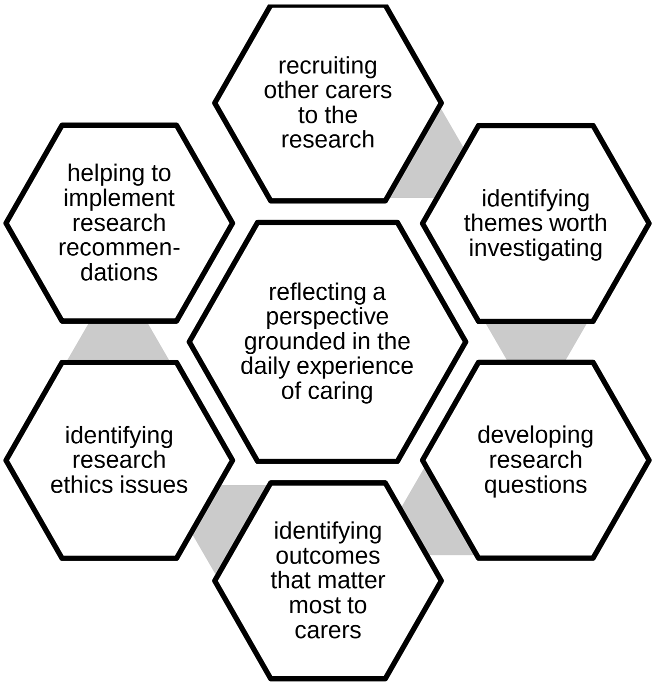


Figure 10: Carers contributing to the evidence base and practice-oriented research

Source: based on Repper et al. (2014)

A participatory approach to research, as suggested by these authors, can contribute directly to generating evidence of benefit to carers. At the same time, it should be recognised that carers on the whole have little time to spare from their daily routines.Engaging with them in meaningful ways in research processes, ‘without imposing additional burdens, is a challenge for all empirical and review work in this field’ (Thomas et al. 2017: 78)

Hansen, Sheehan and Stephenson (2017) examined the role of social media in recruiting carers to research studies. The authors recognised that, for both patients and family caregivers, peer-to-peer health care can result in meaningful online relationships and support in ways not possible before the advent of social media. Recruitment methods included posting invitations on illness blogs, advertising through Facebook, and placing study fliers in community settings.

The researchers found that, while illness blogs and advertising through Facebook was successful, the community fliers generated no interest in the study. Using social media to recruit carers is inexpensive and provides a wide geographical reach. Connecting with carers will require researchers to have an in-depth understanding of how to use social media and other recruitment venues, and it is always important to bear in mind the need to use language in the recruitment materials that family carers could identify with (Hansen et al. 2017).

7 Synthesis

This chapter synthesises the findings from the literature review, drawing the conclusions that enable a response to be provided to the study's research questions (see section 1.3.1). The synthesis addresses:

- Theoretical, policy and practice debates
- Evidence
- Directions for future research
- Making better use of data to benefit carers
- Promoting the evidence base for the benefit of Aboriginal and Torres Strait Islander carers

7.1 Theoretical, policy and practice debates

7.1.1 Carers' participation in education and employment

Commentators agree that, due to socio-economic and demographic changes as the 21st century progresses, public policy will need to support ever increasing numbers of workers to balance informal caring responsibilities with paid work. The point is strongly made by Fine (2012: 66):

> *Maintaining employment must no longer be seen as competing with the needs for care. Instead, we need to act on the knowledge that ensuring good care for those who need it remains an essential condition for the future of the global economy.*

Promoting carers' participation in education and in paid work benefits from the adoption of theoretical approaches that take into account a holistic approach to understanding each carer within her or his social environment (Carmichael et al. 2008). These approaches highlight the fact that a host of factors – personal to the carer, the caring situation, the family and community and the organisational and institutional – impact on carers when it comes to decision-making and action with respect to their schooling, further education and employment. Workplace-related factors such as flexible work arrangements and the innovative use of technology are also addressed in the literature (Fine 2012; Ireson et al. 2018) as variables to consider both when carers are looking for work and when helping them remain in employment.

Combining informal caring duties with education and employment is clearly of importance to young carers (younger than 25 years). However, while it is essential to support young carers with schooling and their progression into further or higher education and employment, there is value to consider this as part of a broader range of supports that help young carers through key life transitions.

Australia has been at the forefront of research (see Hill et al. 2016) which suggests that social inclusion for carers needs to take a more comprehensive account of carers' lives and relationships. While engaging in education and employment are important for carers, a broader focus on their social inclusion would address self-identification issues as well as recognition of the importance of the carer role by families, communities and workplaces. This would then be reflected in policy and in service provision, enabling carers to have wider opportunities for choice in taking on the care role, and to participate in education, in community events and other civil society activities, and in paid work.

7.1.2 Promotion of carer health and wellbeing

Promoting carers' health and wellbeing, with clear benefits also for the people being cared for, is a key focus of the research literature – the conduct of this literature review bears out this contention. The reasons for this interest are clear: study after study, whether in Australia or internationally, points both to the importance of informal carers in contributing to the functioning of health and social care systems, and to their poorer health and wellbeing status compared to the population as a whole. Amongst others, carers experience carer burden, financial difficulties, depression, loneliness and isolation, and poor health outcomes. Many carers do not access any support services for themselves and many are 'hidden' carers.

The search for policies, strategies and programs that effectively promote carer health and wellbeing is an underlying rationale for a great deal of the research in this field. A key factor in addressing carer health and wellbeing is for policy makers and service providers to develop greater understandings of the carer experience itself. The literature is strong on this aspect (see e.g. Duggleby 2017; Day 2015 Hokanson et al. 2018), since research of this nature provides essential insights that enable programs of support for carers to be targeted and effective.

In addition to better understanding different caring situations and caring groups, there is also value in adopting a life-course perspective to understanding caring as a whole (Hamilton and Cass 2017). Such an approach can provide a stronger basis on which to approach policy to support carers and the people for whom they care. For example, as Cummins et al. (2007) showed, the wellbeing gap between the general population and carers becomes smaller in older age groups, providing further support for the adoption of a holistic life-course perspective. Discussion of carer health and wellbeing should not overlook another finding from research that carers report many positive aspects of their caring experiences, since it is these factors that can be drawn upon in promoting self-care and resilience.

The impact of transitions on the health and wellbeing of carers is identified in a many studies (Duggleby 2017; Hamilton et al. 2013; Carers SA 2017. These transitions may be determined by what is occurring in the lives of the people being cared for, as part of the life stage process in general, and of stages in the relationship between the carer and the person receiving care. It is also important to consider the profound impact on carers when their caregiving comes to an end, and to view this as another key transition.

7.1.3 Carer information and community awareness

Strobel and Adams (2015) find that there is a need for improved modes of information provision for carers, including effectively communicating service availability. In order for carers to be open to the information that is directed towards them by governments, communities and service providers, people who have taken on a responsibility with regard to informal caring need to identify themselves as ‘carers’ (Hill et al. 2016). The existence of a carer ‘identity’ also assists members of the broader community to develop awareness of carers. Despite the increase in policies and programs focusing on carers and informal caring, many people remain as ‘hidden carers (Knowles et al. 2016).

Many studies have shown (see e.g. Carers NSW 2016) that carers place a priority upon being recognised and acknowledged. This suggests that community awareness of carers and the role of informal caring is essential because recognition enables value to be placed on their contributions. Awareness of carers, or the lack of it, also extends to service providers. Authors such as Yeandle et al. (2017) suggest that one of the outcomes of feminist theory and practice has been to raise the profile of care work in the public’s eye, since so much informal caring has traditionally been carried out by women.

An issue that may be a source of conflict between carers and service providers is the professional ethic of patient/client confidentiality: a strong sense of protecting the confidentiality of their patients or clients may make it difficult for providers to share information with family members, even primary carers (Greenwood et al. 2010). Adding to the complexity, the information needs of carers may differ in scope and perspective from those of patients (Adams et al. 2009). All of these factors suggest the need for training to enhance the communication and information-sharing skills of professionals.

7.1.4 Engaging carers as partners in care and decision-making

Authors such as Fine (2012) and Rowe (2012) point to the complementarity of informal and formal care in the modern world which necessitates partnerships between carers, the people they care for, and service providers. Compared to previous, even quite recent, periods in history, addressing the needs of people with chronic illnesses or disability, and elderly infirm people is no longer an either-or situation in which care is either provided informally in the family and community, or formally, especially in institutions. A clear outcome of this is that service providers need to engage with carers, both those that self-identify as carers as well as those that are ‘hidden’ carers. Carer engagement occurs both at the level of individual caring situations and at the more systemic level of involving carers as stakeholders in policy and strategic planning processes.

A key issue in addressing carer engagement is the overall approach – often in the form of the organisational or institutional ‘culture’ – that service providers adopt when considering carers as a whole (Wong-Cornall et al. 2017; Morrow and Nicholson 2016). Service providers may view carers as resources and also as co-workers, working in partnership with them; however, when carers are in need of support services themselves, they could be included as co-clients. In all cases, professional service providers require knowledge, skills and attitudes that will equip them to work well with informal carers.

In the context of dementia care, theoretical perspectives support the practice of shared decision-making (Miller et al. 2016), based on the recognition that carers can help to translate the values of the patient into decisions. The flow of information between clinicians and the patient and carer dyad is an important facet of the treatment decision-making process in the case of chronic conditions (Hubbard et al 2010), where the carer acts as a conduit (helping to process the information given by service providers) and as a sounding-board (stimulating thinking about treatment decisions and processes).

7.2 Evidence

7.2.1 Education and employment

Nine studies published from 2008 to 2018 on this theme were analysed in greater detail in this literature review (see Table 2). Studies carried out over several decades have generated findings of relevance to the key issues of carers remaining in or leaving paid employment, strategies to support carers, including carer-friendly workplaces, and employment support for carers.

Drawing on the research carried out by Hill et al. (2008), Arksey and Glendinning (2008), Carmichael et al. (2008) and Pickard et al. (2015), factors impacting on carers' participation in paid work can be stated with a degree of confidence:

- The intensity and duration of the informal care that carers provide
- The nature of the needs of the person being cared for
- Whether and to what extent the cared-for person receives services through the formal care system
- Financial considerations
- The beliefs carers hold about the compatibility of care and paid work commitments
- The trade-offs carers make between the stresses associated with employment and the part that work plays in maintaining, and even enhancing, their socio-emotional wellbeing
- Factors relating to the social security system, such as eligibility rules for Carers Allowance
- Employers' willingness to accommodate carers' needs, including scope for flexible work practices
- The practicalities of distance, transport and commuting.

Since so many factors impact on carers' decision-making regarding employment, adequate support for them to achieve a work-life-care balance require coherent policy measures that cut across traditional government departmental boundaries. These include policies related to employment and workplace relations, social security benefits, health, social services, transport and housing.

International evidence (Ireson et al. 2018) suggests that carer-friendly workplaces are characterised by four key themes: an explicit focus on **employee diversity and inclusiveness**; **employer motivation**, including highlighting the business case of employing carers; **accessibility**, both at the physical level and also at the psychological level, which includes addressing potential stigma associated with carer-friendly work places; and **workplace culture**.

Successful employment assistance for carers includes the following basic elements (NIHR 2014):

- Flexible provision of training courses
- Tailored support to cater for the diversity of carer needs
- Staff with the right set of skills based on qualifications and experience
- Successful partnerships with a wide range of professionals and organisations

This UK study also found that research on employment assistance is poorly developed (NIHR 2014) because the good practice of employment support organisations is rarely taken up, evaluated and implemented more widely, often due to the short-term and unreliable nature of funding.

7.2.2 Carer health and wellbeing

Drawing on 27 studies, 25 of which were themselves systematic literature reviews (Table 3), this literature review has considered research relating to; the caring experience and carers' key concerns; initiatives, programs and services striving to promote carer health and wellbeing, and studies of the effectiveness of these interventions; the helping process; and the experiences and supports needs of carers from Aboriginal and Torres Strait Islander communities.

A strong finding in the literature (see e.g. Abrahams et al. 2018; Carers Australia NSW 2017; Williams and Owen 2009) is that multi-component or multi-dimensional interventions are more successful than single interventions at addressing carers' health and wellbeing needs. According to these researchers, multi-component interventions include, but are not limited to:

- programs addressing carers' needs for knowledge and skills training to better carry out their caring work, including psychoeducation and in-home coaching
- counselling and psychosocial interventions, which may include stress management, mood management and telephone support
- peer support, including face-to-face support groups and online communities
- the provision of respite
- community linkages that provide additional social and community support
- crisis assistance.

Multi-component interventions may be more successful than individual interventions because carers are dealing simultaneously with 'a broad range of stressors' (CarersNSW 2017). The efficacy of multi-component interventions is strengthened by the findings of Parker et al. (2008) that there appears to be little benefit from interventions which only refer carers to support groups, only provide self-help materials, or only offer peer support. At the same time, numbers of systematic reviews included in this study (e.g. Hopkinson et al. 2018; Vandepitte et al. 2016; Lauritzen et al. 2015; Huis in Het Veld et al 2015; Hudson et al. 2010) examine the effectiveness of specific interventions, often for specific groups of carers, since evidence of this nature is essential for strategic planning and best practice. The literature reviewed provides support for the effectiveness of:

- Shared learning, cognitive reframing, meditation and computer-delivered psychosocial support for carers of people with dementia
- Psychosocial interventions, art therapy and counselling for carers of people with cancer
- Counselling for carers of people with stroke
- Support groups for carers of people with mental illness and of people with dementia
- Interventions addressing specific outcomes of relevance to specific carers in a timely way.

(Thomas et al. 2017; Lauritzen et al. 2015; Hudson et al. 2010)

These and other researchers, such as Hopkinson et al. (2018), highlight the need for researchers to state clearly the outcomes that are measured. As findings show in connection with the carers of palliative care patients, for example, interventions based on an individual approach are more likely to have significant effects on carer burden and wellbeing, while interventions based on group approaches work well for building carer competence (Hudson et al. 2010). The literature provides examples of models for classifying the outcomes of carer interventions: for example, Abrahams et al. (2018) suggests that interventions tend to address carer burden, carer depression, carer health and social/community support for carers.

In terms of respite care, Vandepitte et al. (2016) have found that high-quality comparable evidence on community-based respite care is still lacking. In addition, there is some evidence that there are unexpected adverse effects of respite care on both carers and care recipients, pointing again to the importance of measuring explicit outcomes. The Victorian Government (2015) studied the effectiveness of respite provision for the carers of palliative care patients and found that there are limited RCTs that provide high quality research support (see Table 8 of this report for a discussion of levels of evidence) for its efficacy in improving carer outcomes. One of the key challenges for research is that the provision of respite care tends to be delivered within a wider package of services, making it difficult to isolate its unique impacts.

Research by Duggleby et al. (2017) provides evidence for the value of focusing on the relationship-based helping process inherent to caring helping process. Such applied understandings can help service providers to better identify and prepare carers to cope with the 'disruptions' that may ultimately impact on their abilities to continue caring. Granaheim et al. (2014) found that adaption to a new situation on the caring journey (the cared-for person's move into a nursing home) can be facilitated if the family carers continue to be recognised as partners in care, including having regular meetings with staff.

7.2.3 Carers’ access to information and community awareness of the carer experience

Ten studies were included on this topic in a table of evidence, four of which were literature reviews. In addition, three systematic reviews detailed within the health and wellbeing topic (Chapter 3) specifically address information-provision. Provision of information is often considered to be an intervention with carer health and wellbeing outcomes in its own right, often as part of a multi-component intervention (as described earlier). Isolating its specific effects is difficult.

An overall finding from the literature is that more can be done to enhance carers’ access to information. Washington et al. (2011) showed that unmet information needs are prevalent among informal carers of older adults with chronic illness. Day (2015) found that there was a lack of Australian resources targeted the specific experiences of young adult carers. Studies by Bee et al. (2008) and Greenwood et al. (2010) suggest that there may be a reluctance on the part of health care professionals, including GPs, to provide carers with information and guidance. In the absence of adequate information, families typically feel out of control, disempowered to make decisions, and unable to cope with the physical care of relatives on an everyday basis.

Strobel and Adams (2015) suggest that initiatives enabling carers to gain access to services can be grouped into two approaches: through primary health care interventions, where the role of GPs is crucial; and through provision of services to the person being cared for, especially in the home. Both of these provide valuable opportunities for carers to access relevant and usable information. At the same time, there is a lack of high quality research which could shed light on best practice in information provision, including how to improve communication of service availability.

One way to improve the situation would be to develop a comprehensive understanding of carers’ information needs. Based on a systematic review of studies focusing on carers of cancer patients, Adams et al. (2009) generated a framework of carer information needs (see Table 5 in this report) that may be applicable to other carer groups as well. Carers’ information needs go beyond medical information and include non-medical supportive care topics such as dealing with their own emotions and living with uncertainty.

Washington et al (2011) find that timing is important when it comes to information provision – timing relates both to changes in carers’ information needs over time and to the need for proactive information provision i.e. to know what to expect in the future so as to better prepare themselves. Focusing on carers of people with cancer, Kinnane and Milne (2010) found that interactive web-based applications developed specifically for use by carers have the potential to prepare, inform and support them in their ever-expanding role.

There is a dearth of literature on the sub-topic of community awareness of carers and the role it has in contributing to positive outcomes for carers. Surveys carried out by Carers NSW (2016: 12) have shown consistently that carers place a priority upon being recognised and acknowledged. Findings from these surveys show that carers not uncommonly express feelings of being ‘undervalued and underappreciated’. Focusing on young adult carers, Leu and Becker (2017) generate a system for categorising the awareness people have in any jurisdiction about carers and this model could be used to study the awareness of carers in a comparative way, for example, among local government areas. Research focusing on GPs’ awareness of carers (Greenwood et al. 2010) similarly provides insights and approaches that can be tested with other professional and community-based cohorts.

7.2.4 Carer engagement

A total of 16 studies were included in a table of evidence, five of which were literature reviews.

Drawing on findings in the literature, Wittenberg et al (2018) write that carer engagement needs to address at least three themes in order to be effective: division of responsibilities, negotiating the boundaries of the caring role, and collaboration, including recognising and addressing facilitators and challenges to successful collaboration between formal and informal care providers. Carer engagement is particularly important when service systems adopt models such as Consumer-Directed Care (CDC) (Cash et al. 2017) and/or place an emphasis on ‘continuity of care’ (Wong-Cornall et al. 2017).

Factors that contribute to successful engagement and partnerships working between service providers and carers include (Tuffrey-Wijne et al. 2013; Wong-Cornall et al. 2017; Bradley and Green 2018):

- adopting a ‘continuity of care’ model of practice

- service providers having an understanding of the barriers and enablers towards involving carers as partners in care
- staff identifying carer expertise and respecting it
- clarifying respective roles on an individual basis.

Carer engagement issues are especially prominent in research focusing on caring for people with mental illness. There is strong evidence (Ridley et al. 2010) that the quality of engagement and communication between professionals and family carers is a key contributor to effective mental health care. Research provides support for mental health service providers to acquire new skills, undergo a culture shift and integrate the values of carer involvement into their daily practice (Tambuyzer and van Audenhove 2013).

Wallcraft et al. (2011) identified examples of successful partnerships in the mental health setting that could be applicable to other carer groups as well. These partnerships include:

- working with carers to develop the **protocols and guidelines for partnership working**
- carers and service users involved in the **training of professional service providers**
- **committee work** focusing on the planning and management of services
- **regular discussions** outside of work environments between stakeholders.

Researchers and practitioners can draw on the work of Bradley and Green (2018), who stress the importance of making explicit the ‘rules of engagement’ for family input, especially in respect of caring for people with mental illness. These researchers put forward a model that can be applied in future research. Themes within the Rules of Engagement Model are: navigating patient permission; encouraging carers to be present at appointments; two-way information exchange; monitoring, and its links with treatment decision-making; and recognising and addressing differences between staff and family carers.

7.3 Directions for future research

General statements of relevance to the research agenda moving forward include:

- Carer research should be more solidly located in the literature, which includes explicit grounding in the theory and debates as well as in the ever-expanding evidence base.
- Research should be methodologically robust and should ideally employ large sample sizes, validated measures, and mixed method research designs.
- Research should at all times have a strong focus on outcomes and outcomes measures when studying the effectiveness of interventions focusing on carers.
- Longitudinal, comparative and natural experiment research designs all have strong applicability to carer research.

7.3.1 Employment and education of carers

- Continuation of the use of longitudinal data to track the employment of carers in an ever-changing labour market
- Evaluation of services focusing on strategies that assist young carers to transition through their educational milestones and into employment
- Examining and disseminating best practice employment assistance for carers
- Innovative strategies for supporting carers into education and training
- Case studies of carer-friendly workplaces

7.3.2 Carer health and wellbeing

- Build and expand on a solid tradition of scholarship focusing on carer health and wellbeing
- Research on the multi-component interventions best suited to cohorts of carers in specific contexts

- High quality evidence for the effectiveness of specific interventions (e.g. skills training, counselling or support groups) and the dimensions of multi-component interventions on specific outcomes
- Research that addresses systemic and organisational issues, such as care coordination and partnership working
- The experiences of under-served cohorts of carers, such as male carers, and the interventions most effective at supporting them

7.3.3 Carers' access to information and community awareness of the carer experience

- Research to deal with the identified gaps in understanding carers' information needs, especially in light of the impact of the online environment and social media
- More research to examine the impact of information provision on specific carer outcomes
- Research on awareness of the carer experience among professional and community groups as well as in entire jurisdictions

7.3.4 Carer engagement

- Studies that examine the impact of carer-provider partnerships on informational and management continuity within the health services
- Longitudinal studies examining the engagement of carers in models of consumer-directed care, such as the NDIS
- Research aiming to better understand practitioner-carer co-working, and evaluating programs and services in which this occurs

7.4 Making better use of data to benefit carers

- Innovative approaches towards disseminating research findings of importance to carers, including through online means.
- Signposting by health professionals of quality web-based information.
- Involving carers as co-designers of, and active participants in, research.

7.5 Promoting the evidence base for the benefit of Aboriginal and Torres Strait Islander carers

A significant study on Aboriginal and Torres Strait Islander carers was conducted in 2012 as part of an Australian Government initiative (Hill et al. 2012). It identified the following gaps in the literature and recommendations for further research:

- The concept of care and the caring environment in Indigenous communities and how this differs in remote, rural and regional settings.
- The characteristics of Indigenous carers, including those who do not identify as carers, and the people for whom they care.
- Similarities and differences between Indigenous and non-Indigenous carers' experiences.
- The nature and impact of the caring role, including qualitative and quantitative data on the types and patterns of care provided, and the impact of caring on Indigenous carers' lives.
- The assistance Indigenous carers require to support them and how this is best delivered.
- Characteristics of culturally appropriate services.
- Access to, and barriers to accessing, income support payments.

- Barriers to economic and social participation for people with caring responsibilities.

In the years since that important research has been disseminated, there have been initiatives such as the *Carers and Social Inclusion: New Frameworks, Evidence and Policy Lessons* project led by the Social Policy Research Centre at the University of New South Wales (UNSW). This has included reports on the use of ‘yarning circles’ as a valuable research method (see Raven 2016). There have also been studies by, amongst others, Taylor (2013), Hokanson et al. (2018) and Green et al. (2018).

A systematic review of available research has found little quality evidence around Indigenous caregiver functioning (Hokanson et al. 2018). These authors also note that most studies contained numerous methodological weaknesses that compromised the reliability and validity of findings, and they recommend that future research would benefit from greater adherence to the standards that contribute to a strong and reliable evidence base.

Green et al (2018) suggest that the following can be useful in breaking down barriers between service providers and carers and engaging Aboriginal and Torres Strait Islander carers as partners in care:

- Community-led models of care
- Cultural competence programs in mainstream services
- Recognising implicit bias and being aware of inherent power differentials between providers and carers
- Appreciating the social determinants of health and of health care.

Taylor (2013) suggests that making use of comparative research designs has value in better understanding and supporting caring within Aboriginal and Torres Strait Islander communities because useful comparisons can be made with international literature focusing on Indigenous peoples from countries such as New Zealand, Canada and the USA. Hill et al. (2016: 8) identify key factors that are common to supporting Indigenous carers in Australia, New Zealand and Canada:

Figure 11: Key factors in supporting Indigenous carers

Source: based on Hill et al. (2016)

In summary, all of the current research on carers has significance for Aboriginal and Torres Strait Islander carers, but it should be complemented by research focusing specifically on carers from these communities. In doing so, it can also draw on research conducted internationally amongst First Nations and Indigenous carers.

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