Caring Relationships: How to Promote Resilience in Challenging Times

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This chapter examines the potential for resilience within the context of caring relationships, mainly from the perspective of the adult carer. They may be caring for children, spouses or parents with a range of complex problems, such as health or behavioural issues. We will examine the contexts of care provision, exploring what contributes to, or eases the challenge of care provision across the life course. In doing so, we will identify the factors that build resilience for the caregiver in the face of significant challenges.

Resilience Framework

To identify the factors that may promote or detract from resilience, it is important first to be clear about what exactly resilience is, and what we mean when we use the term. The complexities of defining what appears to be the relatively simple concept of resilience are widely recognised, especially within the behavioural sciences (e.g. Haskett, Nears, Ward, & McPherson, 2006; Kaplan, 1999; Luthar, Cicchetti, & Becker, 2000; Masten, 2007; Ungar, 2011). To inform the debate, an extensive review of over 270 resilience research articles, synthesised through the method of concept analysis together with stakeholder validation, generated the following definition:

> Resilience is the process of negotiating, managing and adapting to significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity. Across the life course, the experience of resilience will vary (Windle, 2011).

In the context of caregiving, this definition identifies a number of factors that may increase the risk to the caregiver or act to enhance resilience (see Fig. 18.1). The key point is that the outcome of resilience is not super functioning or flourishing; rather it should reflect the maintenance of normal development or functioning (e.g. mental or physical health), or 'better than expected' development or functioning, given exposure to the adversity under question. This framework is used to inform the chapter and highlights how resilience operates across multiple levels, which interact with each other. These levels reflect the human ecology framework, also described as Ecological Systems Theory (Bronfenbrenner, 1994). Although mainly used for understanding child development, this theory has been receiving considerable attention in the gerontology literature and is cited in the resilience literature (e.g. Harney, 2007; Ungar, 2011) Reflecting this theory, the framework aims to understand people in the environments in which they live and to evaluate their interactions with these environments. People do not exist in isolation but interact with, and are influenced by, their physical, social and environmental contexts.

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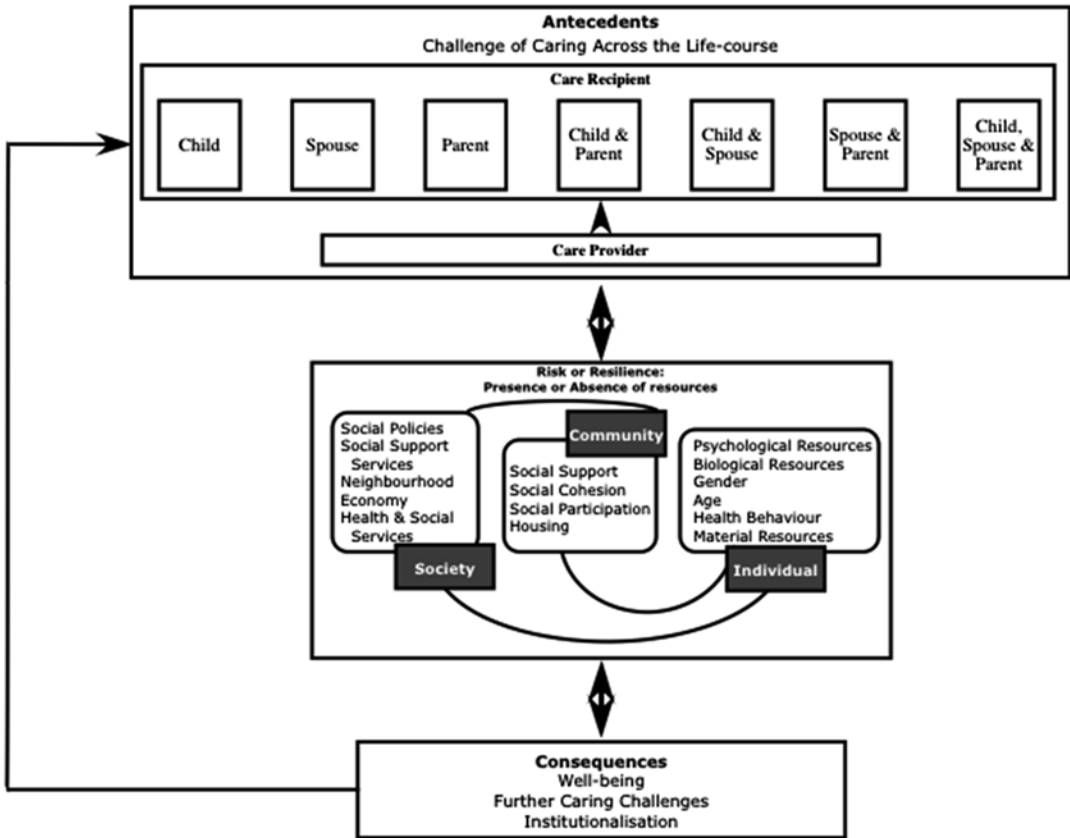Bangor University, Bangor, Wales, UK
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Fig. 18.1 The resilience framework in the context of caring relationships

Methods

For this chapter, we sought information from a number of sources. A previous review of resilience research using systematic principles (Windle, 2011) established a database of research abstracts (1989–2009). These were searched using keyword combinations resilience and carers or caregivers or care providers or social support. A further search was run in Social Sciences Cambridge Scientific Abstracts (ASSIA, Medline, PsycInfo), Web of Science and CINAHL to update those found previously. Statistics on caregiving were identified from population surveys. Broader information on the impact of caregiving was identified in relevant systematic reviews and national policy evaluations.

A Comment on the Evidence

When considering resilience in the context of caregiving, the majority of work in this area has focused on the carers of older adults (≥60 years old) and relatively little has focused on the carers of younger ages. As a result, this chapter focuses more often on caring for older adults, but it is clear that many of the factors that foster resilient caregiving for older adults are relevant to caring for younger adults, adolescents and children with complex needs. Likewise, caregiving occurs across the lifespan, and it is not uncommon for children and adolescents to provide significant care to a parent (Dearden & Becker, 2004).

Caring in the United Kingdom

The increasing rate of informal care given to older adults, in particular, has been driven by demographic changes both in the age structures and in family structures. The last decade of the twentieth century witnessed the effects of increased longevity and increases in the proportion over 60% of national populations. At the same time, fertility is declining. This demographic transition within societies has affected the shape of the family; the number within a single generation has become smaller but the number of living generations has increased. Economists often portray the demographic changes within the context of dependency ratios. The dependency ratio tells us how many young people (under 16 years of age) and older people (over 64 years of age) depend on people of working age (16–64 years). Although there is much debate about the reliability of dependency ratios, these ratios are expected to rise across Europe from 24 to 49% between 2000 and 2050 (Bond & Cabrero, 2007). There have also been considerable changes in household composition and family structure. In most European countries, a trend towards increasing numbers of people living alone and decreasing numbers of three generation or extended family households has been well documented (Tomassini, Glaser, Wolf, Broese van Groenou, & Grundy, 2004). This changing demographic profile can present considerable challenges to caregiving.

Many welfare systems have for some time pursued a policy of community care, which aims to enable people to live for as long as possible in their environment of choice, usually their own homes. In practice, a great deal of help is delivered through informal sources, mainly the family. A recent survey of carers in England found that 12% of people aged 16 years or over were caring for a sick, disabled or elderly person. This equates to 5 million carers in England (National Health Service [NHS] Information Service, 2010). Partners or spouses are most likely to deliver care to a member of the same household. Care provision to a member in a different household is most

likely to be for a parent (Department for Work and Pensions [DWP], 2008/2009). Thirty-five percent of carers in households were looking after or providing special help for a parent, 27% were caring for their spouse or partner and 14% were caring for their child. The remainder of the carers were looking after more distant relatives, friends or neighbours (NHS, 2010).

A recent survey found that 30% of carers were providing care for 35 h or more per week and 22% were providing care for 50 h or more per week (NHS Information Centre, 2010). Informal care of older people is particularly important because of the rising number of older people (aged 65 years and over), especially very old people (aged 85 years and over), in the population. Sixty percent of those receiving care are aged 60 years old and over (DWP, 2008/2009). Older adults have also been noted to provide the most care, with 20% of adults aged 65–74 years and 24% of those aged ≥75 years providing 50 or more hours of care per week (DWP, 2008/2009).

Responding to the effects of demographic changes and trends requires a range of initiatives designed to support carers in their caring role to help them maintain their own health and well-being. In the case of older care recipients, the spousal carers are often older adults themselves and also in poor health. Many other carers are of working age, raising issues concerned with the relationship between caring and paid work, whether the carers are caring for children, young adults, spouses in young and middle age, or parents and parents-in-law. The DWP survey notes that 41% of adult carers were also employed full time. Carers often do not wish to give up their jobs to take on caring responsibilities (Mooney & Statham, 2002). However, the reality for many is that there will be a reduction or cessation in paid employment, which has a serious impact on their financial situation (Department of Health, 1999). Yet, this essential but unpaid support for others makes a contribution worth £87 billion a year (Carers UK, 2008). Given that carers have been regarded as being amongst one of the most socially isolated groups in the United Kingdom (Department of Health, 1999), the potential detrimental effects

of caregiving are substantial. This chapter expands on a number of these issues.

Caregiving Relationships

Informal care is the most important source of care for most older people living in the United Kingdom (Pickard, Wittenberg, Comas-Herrera, Davies, & Darton, 2000). For example, a large proportion of people with dementia continue to live in the community, with the majority of care being provided from unpaid sources such as a family member. Similarly, many physically frail adults also continue to live in the community supported by their families. Spouses are the first to provide care. However, when spousal caregivers are unable to continue to provide care or when they have died, adult children step in, and, therefore, they are the second most frequent source of informal help in old age (Qureshi & Walker, 1990). The benefits of this intergenerational support and solidarity not only concern the provision of care itself, but also contribute to more general quality of life in old age (Tesch-Romer, von Kondratowitz, & Motel-Klingebiel, 2001). It is also known that the importance of support from children increases with age (Tornstam, 1992).

Informal care is also an important resource for younger people and children with a range of needs including physical and mental health problems and intellectual disabilities. For example, parents and siblings provide much care for children, young people and, indeed, adults with intellectual disabilities (Grant & Whittell, 2000), which allow them to continue to live at home. Adults with mental health problems often have spouses and parents who provide care for them when they are living in the community and support for them when they are admitted to hospital (Enns, Reddon, & McDonald, 1999). Indeed, in some cases, it is the children of these people who are providing care, even in adolescence (Shifren, 2008; Shifren & Kachorek, 2003). A survey of 6,178 young carers in the United Kingdom found that their average age was 12 years, and the majority of people receiving care (51%) were

their mothers followed by siblings (31%), fathers (14%) and then grandparents (3%) (Dearden & Becker, 2004).

When thinking about caregiving, one often thinks about caregiving to only one individual, or perhaps to care recipients from the same generation (as with parents or offspring). However, increasingly caregiving may be to multiple persons across multiple generations. Adults in middle age are now termed the 'sandwich generation' (Grundy & Henretta, 2006). The more extreme form of this may be carers in families with a genetic condition such as Duchenne/Becker muscular dystrophy. Kenneson and Bobo (2010) found that some of their participants were caring for more than one person and sometimes across generations. Although they were not examining factors which contributed to resilience, they did find that those with high resilience had higher quality of life. The key question remains – how is resilience achieved under such challenging circumstances?

Caregiver Burden

One of the important benefits of informal care provision at home is that it prevents or delays a move into a formal care environment for the care recipient. This is an often cited critical factor for maintaining the well-being of the care recipient. An overwhelmingly common research finding is that when asked their preference, older people with varying degrees of dependency want to stay in their own homes (Poole, 2006). Residential or nursing care is an unpopular choice, viewed by many as the 'last resort' (Henwood & Waddington, 1998) or unable to meet key areas important for quality of life such as independence and control over decision-making (Burholt & Windle, 2007). However, the challenge of informal care provision can present as a considerable risk for negative psychosocial consequences to the carer, often associated with the chronic stress involved with caregiving (Sörensen, Pinquart, & Duberstein, 2002). Analysis of the 2001 census shows that carers who provide high levels of unpaid care for sick or disabled relatives and friends are more

than twice as likely to suffer from poor health compared to people without caring responsibilities (Carers UK, 2004).

A considerable amount of research has examined the factors associated with the detrimental effects of providing care to older adults; Pinquart and Sörensen (2003) note that over 400 empirical studies examine the psychological effects of caregiving, which largely focuses on caregiver burden. Caregiver burden relates to the overall impact of the physical, psychological, social and financial demands of caregiving. Common psychological problems in dementia caregivers include depression, and emotional distress is common. Carers and those who live with someone with dementia are twice as likely as others to have significant psychological illness (Alzheimer's Disease International, 2009).

The majority of research which has examined resilience in the context of caregiving has focused on the care of older adults. However, research also indicates that poor mental health, chronic stress and poor physical health are found amongst people caring for younger adults and children with complex needs too (Tsai & Wang, 2009; Weiss, 1991; Williams, Donnelly, Holmlund, & Battaglia, 2008). Young carers providing high levels of care can experience friendship difficulties, limited time for social and leisure activities, limited time for school work and home work, which limits opportunities and can make transitions into adulthood more problematic (Dearden & Becker, 2004). Because of caring responsibilities, working age adult carers have less opportunity to earn and many are forced to live on benefits. They also face higher expenses associated with caring, such as higher heating, water and transportation costs (Carers UK, 2008).

Factors Which Contribute to Caregiver Burden

The type of impairment of the care recipient has been found to impact on the extent of caregiver burden. These include the level of physical and functional impairment in the activities of daily living, the amount and duration of care provision, the level of cognitive impairment and the level of behavioural problems. Pinquart and Sörensen produced two meta-analyses, one in 2003 focusing on caregiver burden and depression and the other in 2007 focusing on physical health. With respect to caregiver burden and depression, these were most strongly associated with the behavioural problems of the care recipient, followed by an inverse association of perceived uplifts (satisfaction with caregiving, enjoyable aspects of caregiving, increased closeness) of caregiving and the amount of care provision. They also found that spousal caregivers were more likely to suffer caregiver burden than adult children caregivers with respect to physical impairments and behavioural problems of the care recipient and being a caregiver over a longer duration. The authors suggest that adult children may be more likely than spouses to have alternative roles and social activities outside the home that could moderate the stresses associated with caregiving.

On the other hand, when Pinquart and Sörensen (2007) considered physical health, they found that being a spouse was associated with better health than being a non-spousal caregiver. This is somewhat surprising given the older ages of spouses compared with non-spouses, and one would expect associated poorer health amongst spousal caregivers since they are more likely to be older. However, this might be a selection effect, such that only those physically strong spouses undertake caring responsibilities. With respect to physical health, they also found that increased age, lower socio-economic status and lower levels of informal support were also associated with poorer physical health. The negative effects of caregiving on physical health are most likely to be found in psychologically distressed caregivers facing dementia-related stressors (Pinquart & Sörensen). Again, whilst Pinquart and Sörensen focused on older adults, challenging behaviour, physical impairments and length and duration of caregiving are also relevant factors for carers in general. Enns et al. (1999) found that resilience was lower when stressors such as pregnancy, job entry, and increased job loss, and resources

in particular, communication and esteem and extended family support were lower. Williams et al. (2008) found that amongst carers of people with amyotrophic lateral sclerosis (ALS), physical and mental health was poorer if the carer lived with the care recipient. Unfortunately, the authors did not provide an explanation as to why this was the case.

Gaugler, Kane, and Newcomer (2007) operationalised resilience (or stress resistance) as low perceived caregiver burden and high care demands. In their large study of dementia caregivers, they found that caregiver instrumental activities of daily living (IADL), e.g. preparing meals, shopping, and doing routine house-work caregivers who lived with care recipients, and greater cognitive impairment of the care recipient were negatively associated with high resilience (i.e. higher levels of these factors had a detrimental impact on high levels of resilience). Also negatively associated with high resilience were ethnicity (Caucasian caregivers), greater caregiver education and income. The same study found that caregivers in the low resilience category at baseline were less likely than those in the high resilience category to experience a care recipient death, but more likely to have institutionalised the care recipient or left the study. Thus, it would seem that managing the caregiving role can pose considerable challenges to the balance and stability of informal relationships.

The age of the care recipient also highlights some differences in the potential for caregiver resilience. In Grant and Whittell's (2000) study of carers for people with intellectual disabilities across the lifespan, they found that carers with preschool age responsibilities were different from those with older children and adults. These carers had less self-belief in their ability to control environmental demands. They also had less confidence in their ability to cope, were less sure about their expertise as carers and were also less assertive with the care recipient than those carers caring for older children and adults. Carers of older adults were more resigned to their role and sought less information, and there was a danger that these carers might not seek support when they needed it.

Factors Which Reduce Caregiver Burden

Despite the negative effect of caregiving, other research indicates that even in the face of the challenge of considerable care demands, some carers are less likely to experience these effects. Longitudinal research indicates that caregivers of people with dementia often reported stability or even decreases over time on outcomes such as depression, role overload and role captivity (Gaugler, Davey, Pearlin, & Zarit, 2000). A number of factors have been found to reduce caregiver burden and thus create the potential for resilience.

Buchbinder, Longhofer, and McCue (2009) found that families with children where an adult member had cancer were able to be resilient when they were able to be creative with family traditions, habits and practices. For example, participants would celebrate chemotherapy milestones or ensure that they were always at home for their children's bedtimes. Zauszniewski, Bekhet, and Suresky (2009) found that women caregivers to family members with mental illness were more resilient and had less burden when they were able to employ positive cognitions, such as optimism about the future and considering oneself to be a worthwhile person. Similarly, Grant and Whittell (2000), in their study of carers across the lifespan of people with intellectual disabilities, found that those who were able to manage meanings (e.g. using cognitive coping, rationalising normative conflicts, and embracing paradoxes and experience control were better able to cope than those who did not).

A qualitative study of middle-aged caregivers identified a number of themes related to caregiver resilience. These included (1) experiencing the benefits of caregiving, including personal satisfaction and responsibility, fulfilment and more meaningful relationships, learning to be more tolerant and being able to keep your loved one with you; (2) managing stress through informal support, exercise such as taking a walk, participation in religious activities, hobbies and being able to

take regular time out. Several caregivers had experience of caregiving since childhood and were able to rationalise their time spent caring by envisaging the same would be provided for them, should they need it (Ross, Holliman, & Dixon, 2003).

In a related context, it may be that a sense of obligation towards care provision of close family members makes a positive contribution to resilience (defined as maintaining psychological well-being, e.g. personal growth, despite functional decline). Obligation can be described as the way in which a person is expected to behave towards others. Greenfield (2009) reported that among adults aged 35–74 years, a measure of 'felt obligation' to help close others was protective over time against losses in a measure of personal growth. Thus, having and accepting a sense of obligation may enable the self to continue development and moderate the impact of negative outcomes. Obligation was also identified by Cohen, Colantonio, and Vernich (2002) as a positive factor identified by caregivers. They also found that caregiving was seen as providing companionship, it was fulfilling, enjoyable, and these positive factors were related to reduced caregiving burden. In related research, Gaugler et al. (2007) report that being a female care recipient, having provided care for a longer duration of time and spent more time providing care, having utilised greater formal and informal resources (in-home help services, overnight hospital services and extra help from friends and family), predicted high resilience at baseline, and higher resilience at baseline was associated with lower levels of institutionalisation during the 3 years of the study.

Individuals in stressful situations such as caregiving can benefit from social support networks as they can provide the resources to help them manage their situation. This is highlighted in Pinquart and Sörensen's (2007) meta-analysis. Furthermore, perceptions of the availability of support, and satisfaction with support, are considered to be more consistent predictors of caregiver well-being than the network size and the level of actual support given (Roth, Mittelman, &

Clay, 2005). This indicates that the quality of support is important. Shifren (2008) found that early caregiving experience (caregivers under 21 years of age) influenced later caregiver mental health and relationships with fathers but not mothers. A shorter caregiving experience and the older the age at commencement of caregiving, the more positive the relationship (warmth and care from the father).

There have also been studies of the importance of marital relationships and their impact on reducing (or increasing) caregiver burden and the fostering of resilient relationships. Hodgkinson et al. (2007) studied couples where a spouse or partner had cancer. They found that a high-quality marital relationship increased resilience, both for carer and care recipient. Munro and Edward (2008) noted the resilience of gay men who had cared for their partners who were dying from HIV/AIDS. Their participants had to cope not only with the illness of their partners, but also with the stigma associated with HIV/AIDS. The carer was prevented from accessing support services since the care recipient wanted to be cared for by their loved one to limit the shame and stigma they felt about their illness. They also pointed to the change in role from sexual partner to carer. These results suggest that the quality of the relationship between recipient and caregiver is an important one in facilitating resilience, but this has yet to be empirically tested more widely.

Both social exchange theory (Stoller, 1985) and equity theory (Rook, 1987) have been proposed as potential means of understanding dyadic relationships and their relationship to well-being and caregiver burden. Social exchange theory argues that individuals strive to maximise rewards and minimise costs, in this case in caregiving relationships. Individuals who receive more aid or support than they receive are described as over-benefitting, whilst those who receive less are under-benefitting. Those who over-benefit would evaluate their interactions more positively and have higher morale, and those who under benefit would experience the reverse. However, in some circumstances, over-benefitting can lead to negative outcomes also,

when receiving assistance leads to a sense of dependence or a loss of independence. An extension to this theory is equity theory, which suggests that an imbalance between giving and receiving leads to dissatisfaction.

Wright and Aquilino (1998) tested these two theories in the context of female caregivers, and their care recipient husbands. They found that in terms of emotional exchanges, balanced or equitable relationships led to increased well-being. Tanji et al. (2008) looked at mutuality, that is, the reciprocity of sentiment in a relationship, and found that amongst couples where one partner has Parkinson's disease, greater mutuality decreased caregiver burden and led to lower levels of depression in both partners, but that this pattern was influenced by the severity of the disease.

Yet, others have focused on congruence in coping strategies within caregiving dyads. For example, Pakenham (1998) found that when problem-focused and division of labour coping styles were incongruent, there was less stress for both partners, but that the reverse was the case for emotional-focused coping. Bringing the focus back directly to resilience, Badr and colleagues have examined the importance of relationship maintenance and talk in promoting the well-being of couples where one is providing care to the other. They argue that these lead to resilient relationships and facilitate adjustment (Badr & Acitelli, 2005; Badr & Taylor, 2008).

There is some suggestion of ethnic variations in the social support of caregivers. A longitudinal study examined racial differences in changes in social support and psychosocial outcomes in dementia caregivers (Clay, Roth, Wadley & Haley, 2008). They found that white caregivers were more dissatisfied with their support networks than African-American caregivers, whilst African-American caregivers had fewer depressive symptoms and higher levels of life satisfaction, which was partially explained through their greater levels of satisfaction with social support. The same study also notes that over a 5-year period, caregivers of both races reported declines in the availability of people to provide informal support (Clay et al.). Picot (1995) also reported

that African-American caregivers were seen as more resilient, and that this was explained in part by higher religiosity but also by the use of accommodation rather than problem-focussed coping strategies.

One of the additional challenges to caregiving with respect to resilience is that in many cases the care recipient dies (Haley et al., 2008). Bennett (2010) found amongst older widowers that some of the resilient widowers who had been caring for their wives simply knew how to manage, and this facilitated their resilience both post-bereavement and in their subsequent lives as widowers. But social support, both formal and informal, was also valuable (Bennett). This relationship between bereavement and resilience is more likely with older adults but it is not confined to them. Caregivers may be caring for spouses with terminal cancer (Hodgkinson et al., 2007) or with progressive physical conditions such as ALS (Williams et al., 2008) or HIV/AIDS (Munro & Edward, 2008). It appears that a resilient caregiving experience may contribute to a resilient bereavement experience.

Can Social Policies and Services Facilitate the Resilience of Caregivers?

The previous section identifies the importance of a range of factors rooted within the individual and their immediate social environment that can potentially enhance resilience for the caregiver. Most of these factors are amenable to intervention through society level government action and subsequently could facilitate good outcomes. In an extensive appraisal of the literature, Ungar (2011) synthesises some of the key findings from resilience research together with theoretical debate to argue that the context plays a crucial role in facilitating resilience, and may, in fact, be where efforts should be first concentrated. Individual level resources for resilience may not be activated unless these environments facilitate the opportunities to negotiate, manage and adapt. Here, we explore the role of legislation, policy and services – the institutional environments with which the

caregivers interact. The commitment by the UK government to supporting carers has been described as one of the most 'striking developments' in social policy (Moriarty & Webb, 2000). Within the United Kingdom, each of the devolved nations (Wales, Scotland and Northern Ireland) has developed strategies and legislation for supporting carers. Each introduced a range of initiatives designed to empower carers to take greater control of their lives and to promote a change of culture so that carers are fully acknowledged and respected. The 1995 Carers (Recognition and Services) Act entitled carers of any age, regularly providing considerable amounts of care to an assessment of their needs for statutory support and services. Subsequent legislation has reinforced the right to assessment. Key objectives in the Carers Strategy for Wales Action Plan (Welsh Assembly Government, 2007) state that carers:

- Are not disadvantaged because of their caring responsibilities
- Are listened to
- Maintain as normal a life as possible outside of their caring role, including access to employment, education and leisure opportunities

Although services for carers are not defined in legislation, organisations are encouraged to provide services that maintain carer health and wellbeing (Seddon et al., 2006). Set within the context of a resilience framework, the process leading to and the outcomes of resilience can be better understood.

A synthesis of qualitative and quantitative findings from a programme of carer-related research, including Carer Strategy Evaluation in England and Wales (Seddon et al., 2006) and more specific findings from evaluation of the Welsh Strategy (Seddon et al., 2009), provides some answers for understanding the potential importance of social policy and services in facilitating resilience. This research which sought to evaluate the core aims of the strategies notes a number of difficulties, but also positive findings.

An important factor in ensuring that carer needs are identified to provide support through an assessment. However, only 45% of carers in England and 41% in Wales had received a carer assessment. Although legislation entitles carers to

services, in many instances practitioners are reluctant to administer assessments, fearing that they will identify excessive needs, or because they perceive a lack of time to administer the assessment. In contrast, carers often had few expectations of assessment and presented modest service requests. The most likely service outcome of assessment in England was practical support, such as help with domestic activities and payments to purchase equipment (37%) whilst in Wales it was the provision of respite care (36%). The authors suggest that most carer assessment protocols are narrow in focus with an emphasis on practical aspects of caring, with far less attention paid to psychosocial and relational aspects. Only 3% of carers in England and 4% in Wales reported receiving any emotional support after their assessment. Forty-five percent of all carers in the evaluation of the Welsh strategy reported unmet needs for help. Fifty-six percent who had completed the assessment also reported needs that will still not being met. These tended to be for help such as flexible respite care and emotional help such as counselling support (Seddon et al., 2006).

However, new innovative support services were identified by practitioners as part of changes in care provision (Seddon et al., 2009). These included simple, 'low-level' support services such as help with ironing and gardening, or payments to cover the cost of driving lessons or a washing machine. A range of other services was also identified such as those that enabled carers to remain socially active, carer breaks and skills training to help the carer be better equipped in their caring role, and initiatives to maintain healthy living through flu immunisation and payments to meet the costs of gym membership (Seddon et al.). These practical supports were emphasised by carers as making a substantial difference to their daily lives and were highly valued. Despite the potential of this practical support, most of the carers interviewed had unmet needs for such services.

Thus, there is evidence that the correct assessment of needs and provision of appropriate, good quality services, especially those that facilitate the achievement of outcomes in relation to the key strategy objectives have the potential to

increase resilience in carers. Findings from Pinquart and Sörensen's (2003) meta-analysis led the authors to suggest that interventions that reduce behaviour problems of the care recipient and increase caregiver skills in dealing with behavioural difficulties may reduce caregiver burden. Spousal caregivers may benefit most from services that reduce the objective level of stressors, such as respite care or adult day care.

Further evidence is provided by a review of the effectiveness and cost-effectiveness of support and services to informal carers of older people (Pickard, 2004). The review identified key studies relating to services for carers in England and Wales, existing reviews of services and wider international research. Services reviewed were day care (communal care, provided by paid or voluntary caregivers, in a setting outside the carer's home. Services are usually available for at least 4 h a day); in-home respite care (an alternative form of care at home, where a volunteer or professional may provide a sitter service, or undertake care tasks to enable the carer to take a break); institutional respite care (overnight care provided within residential or nursing homes, community hospitals or intermediate care facilities within the NHS); carer support groups (a mutual support and information sharing service that is directly provided to the carer. Venues and providers vary); social work and counselling (case work counselling, assessing need and implementing packages of care); and home help (a domiciliary service providing help with domestic tasks, self-care and social support).

Definitions of services for carers
Day care
In-home respite care
Institutional respite care
Carer support groups
Social work and counselling
Home help/care

In-home respite care was found to be popular with carers and care recipients; however, the availability of this service is limited and it is not universally available. Day care, home help/care, institutional respite care and social work/counselling services were found to be effective in

reducing the negative psychological effects of caring for carers. Day care was found to be often associated with very high levels of carer satisfaction and benefited carers with paid employment. Small amounts of day care (2 days or less), home help/care and institutional respite care were also found to delay the admission to institutional care of the care recipient, although an inverse effect was found for the latter when looking at groups of people described as having bad user–carer relationships or to be more reliant on others. For these, respite care shortened the length of time in the community. The review notes mixed results regarding the effects of respite care on the care recipient. Many are unwilling to use this type of service as they dislike the idea of going into an institution. The functioning of the recipient was found in some studies to deteriorate, but other studies reported no adverse effects.

Carer support groups were valued by those using them, but the review found no evidence for support groups as an effective intervention and no research had examined the cost-effectiveness of the groups. The same conclusion was drawn for in-home respite care. Day care, institutional respite care and social work/counselling were also found to be cost effective in reducing the negative psychological effects of caring for carers. Thus, services that are effective in supporting carers by supporting the people they care for, and supporting carers directly can improve their welfare and reduce the negative psychological consequences of caregiving.

Discussion

This chapter has examined the potential for resilience within the context of informal caregiving. It is clear that family caregivers are a vulnerable group; their capacities can be compromised by the physical, social, psychological and financial demands of caregiving. Given the current economic climate, where already limited services are likely to be reduced further and unemployment is rising, it is quite likely that the challenges posed by the need for informal care will increase.

It is important to see this challenge and the potential consequences from a lifespan perspective. Whilst most people experience caregiving from middle age onwards, children and adolescents are also the main providers of care in many families.

The limits caregiving imposes on the carer's social and leisure activities presents as a risk factor for all caregivers, although the impact is likely to have different effects. In later life, social networks are established, but the lack of opportunity to forge friendships can pose extra difficulties for young carers, and potentially render them isolated and lonely. In older people, the challenge is further enhanced because of many of the caregivers also having ill-health themselves. For young caregivers, limited time for school work and home work could minimise future employment opportunities.

The chapter has also highlighted the lack of research that has looked directly at resilience in the context of caregiving. Of the studies we identified, the majority focused on adults in mid and later life. Relatively, little work has focused on resilience in young people who take on caring responsibilities in adolescence. Not only do these early experiences focus the need for contexts that facilitate resilience at the time of caring, but also influence the capacity for future resilience (Shifren, 2008; Shifren & Kachorek, 2003).

Given the wide-ranging detrimental impact of caregiver burden, the identification of environments, strategies, services and therapies that have the potential to enhance resilience will be even more crucial for the future. From a society perspective, social policies and the services that they inspire have the potential to facilitate resilience in carers. Supportive environments for caregivers will help ensure that they can continue to face the challenge, function in their role as care providers and maintain their own well-being to the best of their abilities, given the circumstances. In other words, resilience can be achieved if facilitated.

This chapter has identified some of the services and interventions that could facilitate resilience within the caregiving context. Services can be effective in supporting carers directly by strengthening their personal psychological resources so they can find meaning in their role and effectively manage stress. Congruent with other resilience research (e.g. Luthar, 2006), we find that good quality social support and relationships are beneficial to caregiver resilience. Services can also be effective indirectly, by supporting the care recipient. However, far less research has investigated the potential for resilience by examining the carer and care recipient together, or explored the reciprocal aspects of their relationship. Where this has been examined, there is some indication that there may be some conflict between the carer and cared for (Pickard, 2004). Whilst the service might facilitate resilience for the caregiver, the same outcome might not be realised for the care recipient. More research is required to examine the most cost and therapeutically most effective ways to enhance the potential of resilience for both parties.

In conclusion, caregivers are a highly valuable resource to the family members they care for. They enable the care recipient to remain in their own homes, maintaining community cohesion. The care they provide is invaluable to society, and the economic savings to governments are substantial. Ensuring opportunities for developing the resilience of caregivers (and those that they care for) is essential if both are to continue to manage the complex challenges they face.

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