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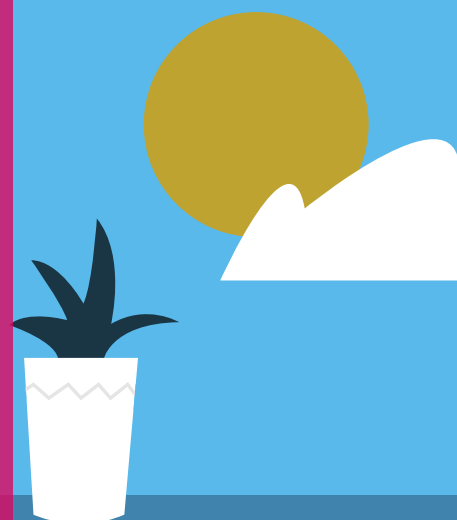
The experiences, needs and outcomes for carers of people with dementia

Literature Review

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Foreword

"This literature review is a crucial step in helping us understand how we can best go about supporting carers "

It is estimated that there are some 700,000 family members or friends of people with dementia providing care in the UK. Carers make a vital contribution to the person they care for and to society. The RSAS plans to support carers to undertake their caring role and to enhance their health and well-being and so improve outcomes for themselves and the person they care for.

The personal experience of providing support and care for persons with dementia is very individual and dependent on many factors. The range and quality of interventions that carers need and find available in their locality also varies considerably.

We are enormously grateful to the Association of Dementia Studies, University of Worcester, for producing this comprehensive and incisive review of the literature currently available that examines the experiences and needs of carers and the evidence of outcomes produced from a wide range of interventions.

This literature review is a crucial step in helping us understand how we can best go about supporting carers. RSAS will use this evidence as a springboard for developing our service offer to carers.

RSAS, in partnership with ADS Worcester University, offer the evidence contained within this document to commissioners and providers across all sectors of care and health services to enable the continual improvement of their support to carers of people with dementia.

Anna Woda
Chair
RSAS

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'The journey through dementia involves considerable changes and challenges, and each family's journey is unique, for them as a whole and for each person within that family.'

Executive Summary

RSAS is developing new and innovative ways of supporting carers, people living with dementia and their families. The charity aims to enhance the health and well-being of carers through providing services that increase their knowledge and understanding of dementia, further enhances their caring skills and provides supportive and therapeutic services to them.

This literature review provides an up-to-date review concerning the evidence in relation to the following questions:

1 What is the experience of caregiving for a person living with dementia, and in what context does caregiving take place?

2 What implications does caregiving have for the person/family member involved in caregiving and the person with dementia?

3 What is currently known about the factors that protect or increase the risk of poor outcomes in caregiving?

4 What evidence is there for interventions to support family caregiving and reduce the risk of poor outcomes and how is this delivered in relation to:
a Information and Education
b Multi-component, psycho-educational interventions
c Psychological Interventions
d Peer support and other social interventions
e Assistive technology and new media

5 What form of service provision is required to support family caregivers? This will include consideration of such issues as:
a How might a service be delivered?
b What factors will influence delivery including location, design, accessibility and flexibility?

6 Who will the service be for and how can family caregivers be supported to engage with the service?

A summary of the results of this review is presented below.

The experience of living with dementia and caring for a person with dementia

Current estimates suggest that around 850,000 people live with dementia in the UK, and 700,000 friends and family are caring for a person with dementia (Alzheimer's Research UK, 2015). It is widely recognised that family members provide the majority of support for people with dementia living at home, and frequently continue to support them following admission to a care home (Woods, *et al.* 2008; Knapp & Prince, 2007; Luengo-Fernandez, *et al.* 2010). These family relationships are particularly important in enabling people living with dementia to experience wellbeing, maintain identity and self-esteem (Livingston, *et al.* 2008).

The journey through dementia involves considerable changes and challenges, and each family's journey is unique, for them as a whole and for each person within that family. The changes and challenges brought about by dementia involve both positive and negative experiences and require that family members engage in an on-going process of assimilation, adaptation and adjustment. It is therefore necessary to consider the impact upon relationships, as well as the individuals within those relationships.

The impact upon relationships

Much of the research has considered the impact upon marital relationships, and less commonly adult children and their parents or other relationship patterns. Consequently, it is important to view these findings with this in mind, as research considering the experience for the diverse range of relationships, including those influenced by ethnicity, sexual orientation, disability and divorce is much less in evidence. The findings concerning the impact upon relationships suggest that:

• Previous and current relationship quality will influence the experience of dementia. Some evidence suggests that higher satisfaction occurs with caregiving where previous and current relationship quality is high.

However it cannot be assumed that this will result in better outcomes for all family members.

• Poor relationship quality may result in conflict and disconnectedness.

• Changes occurring as a consequence of dementia include loss of companionship, shared interests and mutual support, but research also suggests that love, warmth and affection are still possible.

• Dementia often also involves a change in the relationship itself, moving from partners or parent child to carer and cared for, frequently such changes require a complex process of negotiation between family members.

• Some family members seek to support the person with dementia to retain their roles and their identity for as long as possible.

• Open communication is necessary within relationships to support adaptation to the challenges dementia brings.

The impact upon individuals

Evidence on the impact and experience of dementia for individual family members is variable, with studies on spouse and adult children (usually daughters) being more frequently found. However research indicates both similarities and differences in the experience for individual family members, necessitating that their experiences and needs are considered separately.

The person living with dementia

• The experience of dementia can render people vulnerable to their psychological defences being broken down, meaningful and supportive relationships are essential to the maintenance of wellbeing.

• People with dementia are active in seeking to adapt to live with dementia, which includes developing practical, emotional and relational strategies.

• Changes in functioning occur from early in the experience of dementia and progress, people with a diagnosis describe the importance of remaining independent and actively seeking ways of adapting to the difficulties, demonstrating the continued importance of a sense of agency and control over one's life and maintaining valued activities and occupation.

• Research suggests that decreases in wellbeing of the person with dementia correspond with increases in stress and distress experienced by their family caregivers. Thus interventions which involve improving the well-being of people living with dementia alongside their family caregivers are likely to be an important factor influencing outcomes.

Spouse/Partners

• The experience of caring for a spouse/partner is intrinsically related to the relationship in which caring takes place.

• Caring often takes place in the context of a long established relationship characterised by degrees of commitment, satisfaction, and sharing of roles. Consequently, many spouses/partners may not view themselves as carers.

• Relationships between spouses/partners can increase the risk of or protect the family member from experiencing poor mental health as a consequence of caregiving.

• Spouses/Partners may invest considerable energy in providing care, and may do so to the detriment of their own wellbeing.

• There are gender differences in caregiving in this context, which will influence the type of coping strategies used and the support that they wish to receive.

• Spouse/Partner caregiving involves both satisfactions and costs.

- The impact of caregiving for spouse partners is known to be significant, and includes a range of psychological, physical and social outcomes including high levels of depression and loneliness, and stress. Such outcomes arise from a range of factors including:
  - the quality of the previous and current relationship;
  - the motivations and meanings associated with caregiving;
  - the coping strategies used by spouses to manage the challenges brought about by dementia;
  - the losses associated with dementia;
  - the behaviour of the person with dementia;
  - the supportiveness of family and social networks; and
  - the health and well-being of the person with dementia and the spouse caregiver.

Adult children

- Adult daughters are the most common caregivers for people living with dementia after a spouse, but increasing numbers of sons are also providing care, as are children-in-law.

- Adult child caregiving is frequently defined by social norms concerning independence/ interdependence within the family, community and society.

- Caregiving in this context is frequently characterised by living separately from the person with dementia and having additional familial, financial and occupational responsibilities.

- Gender differences are evident in coping styles.

- Caregiving for a parent requires a considerable renegotiation of roles, which may challenge boundaries within the relationship. It can also bring past conflicts and ambivalent feelings to the surface, as well as providing opportunities for reciprocity and continued expression of commitment.

- Motivations for providing care will influence the experience and outcomes associated with caregiving.

- The quality of the relationship is an important factor influencing outcomes.

- The experience of caregiving is associated with increased risk of poor outcomes, including stress and poor health.

- Changes in the relationship and the behaviour of the person with dementia increase the risk of placing the person with dementia in a care home.

- Greater levels of family conflict are experienced where disagreements about the balance of caregiving activities between family members occur.

- Adult children are more likely to use services such as respite and day care and gain benefit from them.

Children/young people

- Children and young people may experience dementia in the family in a grandparent or less commonly, a parent.

- Relationships with parents and grandparents are fundamental to children's wellbeing.

- Children and young people are affected psychologically and developmentally by the onset of dementia in a family member particularly if they are living with the person with dementia. They are unlikely to have the cognitive functions and resources to cope with caregiving stressors and manage their own needs.

- Parents and grandparents involved in caregiving may struggle with the time commitments involved and this may impact on the time they have available for their children.

- Having a grandparent with dementia can result in positive experiences but requires their parents and grandparent without dementia to talk about what is happening, to provide appropriate levels of information and support to manage the difficult behaviour of the person with dementia.

Executive Summary

- Negative experiences include feelings of guilt, frustration, loss and sadness.

- Having a parent with dementia presents particular challenges for children and young people, which are compounded by low levels of service provision and understanding.

- The impact of dementia on the relationship between parent and child is considerable, often involving a degree of detachment and a reversal in roles.

- School life can be affected, with children experiencing embarrassment because of the behaviour of the person with dementia and intolerance of school friends.

- Children and young people are actively involved in caregiving, although they do not necessarily see themselves as carers. They provide practical and personal support as well as help with household activities.

- Involvement in caregiving may increase maturity, but may also cause considerable stress and burden in children.

- Children and young people need specifically tailored information and education, psychological support, assistance to manage the behaviour of the person with dementia and peer support.

The impact of caregiving for particular groups within society

It should be acknowledged that there are some limitations in the research, including that it largely reflects relationships within traditional family structures, and predominantly spouses. However family relationships and caregiving are affected by a range of factors including ethnicity, sexual orientation, gender, disability and divorce. Thus it is also necessary to consider available research evidence for the impact and experience for different groups within society. The impact of less common forms of dementia will be considered later in the review.

Caregiving within migrant and minority communities

- Ethnic background has a significant influence on a person's perception of dementia, caregiving experiences and use of formal support services.

- Migrant and minority communities represent a diverse range of cultural groups – for example, people who are of Asian Indian, Caribbean, Mediterranean and Irish origin, as well as indigenous people born to migrant parents and grandparents.

- Early onset dementia and vascular dementia are most prevalent in Black Caribbean and Asian Indian communities.

- Additional challenges for caregiving in this context exist, associated with cultural and community norms, language, literacy and the stigma of mental health.

- Kinship patterns of help are changing but care is still largely negotiated within family members.

- Role reversal can be particularly problematic for Asian older women, and social isolation post migration results in difficulties with tasks that involve being out in the public domain.

- Resilience for male Sikh carers is evident because of the levels of self-efficacy required to cope with migration to the UK.

- Expectations to adhere to community values may create further complications when these conflict with individual needs, and may result in feelings of isolation and depression.

Caregiving for younger people with dementia

- Only a small body of evidence explores the experience of dementia for younger families.

- The family experience of dementia at a younger age is influenced significantly by the life stage at

which it occurs, involving significant responsibilities such as work, mortgages and other financial commitments and other dependent family members including children and young people.

- Caregiving is associated with frustration, grief and guilt, loneliness and social isolation.

- Poor psychological wellbeing is a consequence of caregiving, particularly for female and spouse caregivers.

- Challenges experienced are also associated with the less common forms of dementia that are more prevalent at a younger age, which result in behaviours which are difficult to manage, and cause social embarrassment and fundamental changes in relationships.

- High levels of burden, depression and family conflict are associated with family care of younger people with dementia.

Experience of people from LGBT communities

- The LGBT communities are complex with varied experience and needs, not a heterogeneous single community.

- There is a growing recognition that (LGBT) people with dementia and their needs are underrepresented in dementia services and in the strategic development of dementia support.

- LGBT people have a range of relationship forms which may not follow typical heterosexual patterns, their relationships and their families may be more strongly based on "choice" rather than blood ties.

- Their concerns included: facing negative reactions to their sexuality, being forced 'out', losing contact with gay and lesbian friends and networks, losing control of their own lives, isolation and marginalisation.

Caregiving for people with learning disabilities and dementia

- People living with Down's syndrome have an increased risk of developing Alzheimer's disease, beginning at an early age. The average age of onset is mid 50's.

- People with learning disabilities are living longer; consequently the prevalence of dementia is also increasing among this population.

- Limited evidence is available concerning the experience of caring for a person with a learning disability and dementia.

- Families may lack knowledge that a person with a learning disability can develop dementia and experience difficulties in obtaining a diagnosis due to the differences in initial symptom experience.

- There may be a lack of networks to support families in this position.

- The emotional impact of a diagnosis of dementia, in addition to the original diagnosis of a learning disability may be a considerable emotional challenge for family members.

Experience of service use

- Families experience significant challenges in accessing services which are appropriate to their needs and the needs of the person living with dementia

- These challenges begin at the point of suspicion that something is wrong, and continue throughout their journey with dementia, and are influenced by such factors as age, ethnicity, sexual orientation, gender and living situation. These difficulties are influenced by a range of factors including:
  - Knowledge and attitudes of the general public;
  - Knowledge and attitudes of professionals;
  - Beliefs about dementia, influenced by lack of

understanding and stigma, absence of the concept within specific cultures, attribution of symptoms to normal ageing, or other health difficulties;

◦ Denial; and

◦ Lack of co-ordination within and between service systems.

• Evidence from consultations with people living with dementia and their family members have emphasised the considerable variability in what people believe they need, but core themes about services can be drawn from such research. These themes include:

◦ People living with dementia and their families want support to enable the person living with dementia to remain at home as far as this is possible;

◦ People value early assessment and diagnosis and a significant proportion of people wish to know their diagnosis;

◦ Following diagnosis, people identify the need for individualised and tailored information and education about dementia, available in a variety of forms and accessible throughout the journey with dementia;

◦ An ongoing point of contact through the journey with dementia;

◦ Access to appropriate treatment and support when this is needed; and

◦ Interventions that are responsive to their particular circumstances and needs.

What implications does caregiving have for the person/ family member involved in caregiving and the person with dementia?

There are a number of known outcomes related to family caregiving, these outcomes can be summarised in six main areas:

1 Deterioration in the physical health of the family caregiver, including heart disease and reduced immune functioning.

2 Deterioration in the psychological well-being of the family caregiver including depression and lowered quality of life.

3 Psychosocial consequences, including isolation and changes in relationship quality and conflict within the family.

4 Admission to institutional care for the person with dementia.

5 Abuse.

6 The financial impact of caregiving, including having to leave employment as a consequence of caregiving.

Factors that protect or increase the risk of poor outcomes in caregiving

Research concerning the outcomes of family caregiving, the factors contributing to these outcomes and the development of interventions designed to prevent such outcomes has largely been influenced by theoretical models concerning the experience and impact of stress, in particular the Stress Process Model (Pearlin, et al. 1990) and the transactional model of stress and coping (Morrissey, et al. 1990). Descriptions of these models can be found at: http://gerontologist.oxfordjournals. org/content/30/5/583.full.pdf and www.youtube.com/ watch?v=a8FEMHCRowM respectively.

A range of factors are considered to be either protective or contribute to the development of poor outcomes in caregiving. However, the identification of risk factors is complex. One major research study highlighted that:

• In the main, the patterns of risk are unique to each family caregiver;

• An association between the caregiver's health behaviour and stress-related outcomes was identified, but this could occur either positively or negatively;

• Family caregivers may have improved outcomes because they take care of themselves, or depression may lead them to neglect their health;

• Risk assessments for caregivers need to be planned carefully and interventions need to be targeted in terms of the appropriate risk factors and outcomes.

The factors that may protect or increase the risk of poor outcomes can be grouped under five main areas:

Psychological aspects

- Psychological Resilience (including perceived control and response to challenge in one's life).

- Religion and spirituality.

- Self-efficacy.

- Experience of service use and service response.

- Experience of less common forms of dementia, involving the specific symptom experience and the meaning these changes have.

- Communication styles.

- The meanings and motivations associated with caregiving.

- Meaning of the changes in behaviour for the family caregiver.

- the caregiving context, including:
  - the gender of the family caregiver;
  - the nature, duration and intensity of caregiving; and
  - the living arrangements between the family member and the person living with dementia.

- The wellbeing of the person with dementia. Coping styles, including solution focused coping, coping based on acceptance and garnering emotional support and problem solving.

Physical factors

- Sleeplessness.

- Depression is linked to cardiovascular pathology.

- Chronic and multiple acute stressors, also linked to cardiovascular pathology.

- Psychological factors may combine together to increase risk of dementia and other health difficulties.

- Autoimmune and metabolic disorders arising from stress.

- Self-care.

Relationship, social support and familial factors

- The influence of familial, cultural and societal norms and how these correspond with individual needs.

- The quality of the previous and current relationship.

- Quality of family support.

Factors related to abuse

Factors above can combine together to increase the risk of abusive behaviour by the family caregiver but these risk factors also include:

- The frequency and intensity of provocative/aggressive behaviour from the person with dementia; and

- The nature of the coping strategies used by the family caregiver, including coercive strategies.

Cultural competence of services and knowledge of dementia among migrant/minority communities

- Knowledge and understanding of dementia within different cultural communities

- Stigma associated with dementia.

- Poor detection leading to help seeking in crisis.

- Lack of cultural competence within health, social care and third sector agencies.

Who is at greater risk of poor outcomes?

While it is evident that there is considerable individual variability in the experience of caregiving, there is evidence that certain types of family caregivers are at greater risk of poor outcomes. These are:

- Female caregivers, who are more often depressed;

- Spouse caregivers are more often depressed than other caregivers;

- Possibly people from migrant or minority communities but further UK research is required;

- Family caregivers of younger people with dementia;

- Where the severity of the dementia and the dependence upon the family caregiver is high, but further research is needed to understand this relationship; and

- Where pre-existing disabilities are present, such as a learning disability, but further research is required.

Assessment of factors influencing outcomes

Assessment is a fundamental aspect of delivering effective interventions for family caregivers, in order that the right interventions are offered. Due to the wide range of risk factors identified above, assessment needs to be multidimensional and include developing an understanding of:

- Context of care;

- Family caregiver perception of the health and functional status of the person with dementia;

- Family caregiver values and preferences;

- Family caregiver well-being;

- Consequences of caregiving;

- Skills/abilities/knowledge to provide care; and

- Potential resources.

Interventions to support family caregiving and reduce the risk of poor outcomes

A large number of psychosocial interventions have been designed to address the factors that influence negative outcomes in caregiving. Given the significant number of interventions available in the literature, a number of systematic reviews, meta-analyses and reviews have been completed in recent years, and have identified the interventions and the characteristics of those interventions that have demonstrated the most success. When viewed together, the results of this review indicate that successful interventions:

- Recognise that family members have a heterogeneous profile of factors

- Are multi-component and tailored to the needs of the family caregiver and include;
  - the involvement of the family caregiver in deciding what forms of intervention are required;
  - the involvement of the person with dementia in order to address their wellbeing needs;
  - providing opportunities to address the relational context in which caregiving takes place;
  - a combination of individual, family and group interventions depending upon the needs and wishes of the family caregiver and the person with dementia; and
  - Actively involve the family caregiver in the development of acceptance based coping strategies.

- Are provided by skilled and experienced practitioners.

- Are structured, providing at least six sessions and are followed by on-going support, all of which can be provided flexibly to respond to the needs of the family including the use of telephone, video-conferencing

or computer based technology as well as face to face, which may assist in translating research based interventions into practice.

- Are designed to address the development of coping strategies and enhance resilience, which include the family caregiver as an active participant in this process.

- Include the delivery of a range of possible processes including:
  ◦ providing emotional support and assistance;
  ◦ providing counselling and psychotherapy;
  ◦ enhancing family and support networks;
  ◦ developing communication skills and strategies;
  ◦ self-care strategies;
  ◦ knowledge concerning support services;
  ◦ knowledge of dementia and strategies to understand and cope with distressed; behaviour of the person with dementia;
  ◦ meaningful activity and occupation; and
  ◦ stress management techniques.

- Use cognitive behavioural methods other models may have efficacy but this has not been established due to a lack of research.

- Are provided when the family caregiver identifies the need for support, which may be at different points in the journey through dementia, but will include immediately following diagnosis and at key transitions in the caregiving pathway.

- Address the psychological and self-care factors that contribute to or mediate against poor outcomes as these appear to also influence physical health and wellbeing.

While many interventions have been evaluated, various reviews have highlighted the challenges associated with the methodologies of these studies and in the real life translation of them into practice. A few studies have proven efficacy over time and in translation to clinical practice, including the

NYU Intervention Programme (Mittleman, *et al.* 2004a, 2004b, 2008) and REACH II (Schulz, *et al.* 2003; Belle, *et al.* 2006; Nichols, *et al.* 2011; Stevens, *et al.* 2009; Au *et al.* 2010).

Gaps in psychosocial interventions

A number of gaps are evident when exploring the research concerning psychosocial interventions. Here in summary:

- There is a need for further investigation of interventions which are excluded from most studies because they do not meet evidence based standards, e.g. grass-roots derived caregiver support groups and complementary and alternative therapies.

- Despite prevalence studies pointing to high levels of elder abuse few studies have looked at interventions with caregivers to reduce the risk of abuse.

- More research is needed on how to provide accessible and appropriate, targeted information about dementia and available services to ensure that people with dementia and their and family carers can be aware of early signs of dementia and seek help at an early stage.

- Further evidence is needed on accessible, practical interventions for caregivers' physical health, including work on encouraging caregivers' self-care, exercise and healthy living, and promoting sleep.

- Implementation studies are needed on how to make existing interventions which are known to have an effect on burden, stress and depression available more widely to people at risk of exclusion including people from a range of cultural and ethnic groups, LGBT people, people in rural areas.

- More research is needed on what helps families who are caring for a younger person with dementia.

- Evidence is required to understand what works for families who are affected by less common forms of dementia.

- More long term follow-up studies would help to better assess the sustainability of outcomes of interventions, and the differing needs caregivers have at different stages.

- Research should, where possible, give more attention to sub-groups of caregivers and the difference in outcomes from intervention for these groups.

- No research has been identified which compared income groups, or social class groupings, and no research has addressed LGBT caregivers or persons with dementia.

- More research is needed on interventions for the specific cultural and ethnic groups living in the UK.

What might a service be like?

Factors influencing the success of psychosocial interventions

There are a range of factors that influence the success of interventions that will be relevant when considering their provision. These include:

1 Interventions should clearly identify the theoretical framework/s influencing their design and delivery.

2 A comprehensive and individualised assessment of the needs of the family caregiver should be carried out and the results of these assessments used to inform the type of intervention delivered.

3 Staff who deliver such interventions need to have appropriate training and education and be knowledgeable and skilled in delivering assessments and interventions.

4 Evaluation of intervention efficacy should be built

into the interventions at regular intervals so that appropriate adjustments can be made. Such evaluations need to be linked to the theoretical framework informing the intervention.

The Built Environment

Although there is an increasing evidence base for interventions that are provided through new media such as the internet or videoconferencing, many existing interventions are at least in part group or family oriented and face to face, and thus frequently require a physical space for delivery. Therefore, the physical design will need to be considered. Evidence in this area suggested that:

- Buildings that support activity by providing effective assistive devices, giving people control of their environment and affording good links with the community have a positive association with well-being.

- Poor design can lead to the marginalisation of people with physical frailties and/or cognitive impairment.

- Outdoor spaces are also important, including gardens, balconies and courtyards, because they provided additional space as well as opportunities to take part in activities such as gardening.

- Adaptations and assistive technology can be cost effective, with relatively short investment pay-back periods.

- Creating small, familiar environments; incorporating unobtrusive safety features; good signage; and the use of colour, lighting and architectural landmarks to aid orientation and way-finding are important principles of environmental design for people with dementia.

- Initiatives such as the Enhancing the Healing Environment Programme and The Maggie's Cancer Caring Centres Model are available to influence design.

Who will the service be for and how can family caregivers be supported to access a service?

Who will the service be for?

This review has highlighted that a range of family caregivers are involved in caregiving including:

- Spouses/Partners of people living with dementia (including long-term marriage and partnerships, those in second relationships and partners in gay and lesbian relationships).

- Adult children, including daughters, sons and their partners/ spouses.

- Children and young people with a grandparent or parent with dementia.

- Siblings and friends may also be involved in caregiving.

A wide range of family caregivers, influenced by diverse backgrounds, ethnicity, sexual orientation, relationship and gender are therefore likely to be involved in caregiving and may benefit from tailored interventions.

How can people be supported to access the service?

A range of factors are known to influence access to services, including:

- The flexibility of the service to respond to the different circumstances of family caregivers, for example work and family life commitments, disability, and sensory impairments.

- The availability of transport links.

- The availability of support for the person with dementia if the intervention does not include them.

- The needs of specific communities and migrant or minority groups within those communities.

A service will therefore need to consider developing interventions that respond flexibly to the needs of different families, through:

- Use of new technologies such as the internet, video or telephone conferencing. Key to delivering these however will be the availability of such facilities for family caregivers and will need to consider that:
  - Some sections of the community, including older people who are caring for spouses or partners with dementia may not have access to such facilities
  - Many younger family caregivers will have access to these facilities, now and in the future, and may value this form of intervention.

- Migrant and minority family caregivers would benefit from a service that is well linked into the local communities for which it is serving.

- The service should demonstrate a value base that promotes inclusivity by treating such members as individuals alongside the knowledge of the social and political influences in their lives as migrants.

- Based on the evidence, additional work may be required to access migrant and minority communities and encourage them to engage with the service; particularly the older generation who may also have language barriers.

- Develop links with networks that support people from LGBT communities

- It may therefore be helpful to include community-based outreach approaches which embrace an appreciation for caregivers' faith development, expressions and experiences of spirituality.

'Research suggests that specific types of family caregiver intervention programmes have considerable potential to improve the quality of life of family caregivers and people with dementia and reduce negative outcomes in care.'

Full Report

Introduction

Current estimates suggest that around 850,000 people live with dementia in the UK, and 700,000 friends and family are caring for a person with dementia (Alzheimer's Research UK, 2015). It is widely recognised that family members provide the majority of support for people with dementia living at home, and frequently continue to support them following admission to a care home (Woods, *et al.* 2008; Knapp & Prince, 2007; Luengo-Fernandez, *et al.* 2010). These family relationships are particularly important in enabling people living with dementia to experience wellbeing, maintain identity and self-esteem (Livingston, *et al.* 2008).

Caring at home for a family member living with dementia is known to incur considerable demands. The daily challenges include supervision, managing the impact of the changes experienced by the person with dementia and coping with the changes that occur in relationships. The carers in the recent Alzheimer's Research UK (2015) study demonstrated a limited understanding of dementia and how it progresses. They were much more aware of the impact on behaviour, but little desire to understand how the dementia might develop, they were more inclined to live day by day.

While some family members report satisfactions in caregiving, and indeed being able to continue to work together and maintain meaningful relationships (Keady & Nolan, 2003; Hellström, *et al.* 2007), many family members involved in care-giving also experience high levels of stress, depressive symptoms, poor physical health and social isolation (Brodaty, *et al.* 2007). Furthermore, evidence suggests that levels of stress and distress increase over time, as the changes arising from dementia progress and become wide ranging in their effect and impact upon the person living with dementia (Froelich, *et al.* 2009; Kannan, *et al.* 2011). These experiences have been studied extensively, as have methods of alleviating them (Mittleman, *et al.* 1995; Marriott, *et al.* 2000; Livingston, *et al.* 2005; Selwood, *et al.* 2007).

Research suggests that specific types of family caregiver intervention programmes have considerable potential to improve the quality of life of family caregivers and people with dementia and reduce negative outcomes in care (e.g. Mittleman, *et al.* 1995; Marriott, *et al.* 2000; Livingston, *et al.* 2005; Selwood, *et al.* 2007; Brodaty, *et al.* 2007). While it is not possible to influence the physiological course of the disease, it is possible to influence the psychological and social factors impacting upon the family caregiver and thus their ability to care.

Furthermore, recent developments in research have highlighted that some family members fare better in regard to their care-giving experience than others and that there are various factors that may influence a less positive outcome, including the quality of the previous relationship, social support, personality factors and ethnic background. Alongside this, it is recognised that those involved in care-giving in this context may benefit from targeted interventions early in their experience of caregiving to prevent negative outcomes in care (Marziali, *et al.* 2010; Balducci, *et al.* 2008). However it is also clear that implementing the findings of such research studies into 'real world' work with family caregivers is a considerable challenge due to availability of skilled practitioners, intensive protocols and the costs associated with such interventions (Stevens, *et al.* 2009).

Nevertheless, given the rising numbers of people living with dementia, and the impact of caring for people living with dementia, including the significant health and economic costs associated with dementia (Prince & Jackson, 2009; Alzheimers Society 2014), it is increasingly acknowledged at a national and international level, that family members should be supported in caregiving roles. Prince, *et al.* (2011) identified the need for an earlier diagnosis to enable people with dementia and their carers/families to take advantage of appropriate support and services, such as the formation of new peer relationships to 'share feelings, information and coping strategies' (Prince, *et al.* 2011, p28).

The implementation of the National Dementia Strategy for England (2009) and subsequently those in Scotland, Wales and Northern Ireland acknowledge the need to provide appropriate levels of intervention for family caregivers. This is further reinforced in the Prime Minister's Challenge (Department of Health, 2012, 2015). These and related policy documents highlight a number of priorities which include the provision of information, education and support for people living with dementia and their families and carers. Elvish, *et al.* (2012: 3) identify three key statements within the strategy which require action:

- Active work is needed to ensure that the provisions of the Carers Strategy are available for carers of people with dementia.

- Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality personalised breaks.

- Action should be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

It is within this context that RSAS is seeking new and innovative ways of improving the quality of life for people living with dementia and their families at home. The charity wishes to contribute to improving the quality of life for people living with dementia, by providing support to their carers and families, so as to enable them to live at home and within their community for long as possible. They wish to achieve this through the design and delivery of a project or service model which can provide support to carers and families of people living with dementia at home to ensure that they can maintain their independence, their dignity and remain in their own homes for as long as possible.

This literature review forms the first stage of this development and provides an up-to-date review concerning the evidence in relation to the following questions:

1 What is the experience of caregiving for a person living with dementia, and in what context does caregiving take place?

2 What implications does caregiving have for the person/family member involved in caregiving and the person with dementia?

3 What is currently known about the factors that protect or increase the risk of poor outcomes in caregiving?

4 What evidence is there for interventions to support family caregiving and reduce the risk of poor outcomes and how is this delivered in relation to:
   a Information and Education
   b Multi-component, psycho-educational interventions
   c Psychological Interventions
   d Peer support and other social interventions
   e Assistive technology and new media

5 What form of service provision is required to support family caregivers? This will include consideration of such issues as:
   f How might a service be delivered?
   g What factors will influence delivery including location, design, accessibility and flexibility?

6 Who will the service be for and how can family caregivers be supported to engage with the service?

'It is within this context that RSAS is seeking new and innovative ways of improving the quality of life for people living with dementia and their families at home.'

Method

Criteria for the initial literature search were identified in February 2013, using the following search terms:

- Careg* AND Dementia AND Risk OR Assessment OR Interventions OR Outcomes as the central focus limited to 2009 onwards.

- Careg* AND Dementia OR Alzheimer's Disease AND Black and Minority Ethnic Community* OR African Caribbean OR Asian OR Eastern European OR Indian OR Traveller OR African OR Pakistan* OR Bangladesh* OR Chinese OR Arab OR South Asian OR Polish OR Irish from 2000 onwards.

- Assistive technology AND Careg* AND Dementia from 2005 onwards.

The original review was refreshed in March 2016 repeating this methodology. A total of 1493 abstracts have been obtained. Titles and abstracts were reviewed according to the following inclusion criteria:

- Primarily published since 2009 (seminal papers included as appropriate).

- Family Caregiver interventions.

- Dementia.

- Concerned with 'real life' outcomes and longer-term impact of interventions.

- English Language.

Further searches were carried out through identification of references cited in key articles and review of the 'grey literature' as appropriate to the area under investigation. 454 articles were initially selected from the completed searches.

References were read to obtain the core results and to identify their relevance to the different sections, after which 304 references were selected for inclusion, which were primarily published between 2009 and 2016. References include meta-reviews, systematic reviews, systematic syntheses, controlled trials, qualitative studies, reviews and a few small studies e.g. single case studies where these shed light on under-researched issues. Papers of a seminal nature were also sought and included in the review as appropriate to the issue being studied. Furthermore, the authors also drew upon their knowledge and networks in this area to select reports, books, book chapters and publications that did not appear in the search. Finally, sources of 'grey literature' were included as appropriate. References were excluded from the review where they were:

- Inconclusive in regard to efficacy of intervention

- Included in previous systematic reviews

- Conference abstracts

- Covering populations not relevant to UK migrant or minority communities

Ultimately 326 references were sourced and used within this review, including references made to policy and practice guidelines. This review has a number of limitations. Firstly, the references reviewed were restricted to English Language only, thus references available in other languages have not been included.

Secondly, references reviewed were primarily limited to publications within the last four years. Thirdly the articles reviewed predominantly reflect research, policy and practice derived from Northern and Central Europe, USA and Canada.

"Life is becoming much more difficult, and Paul needs to be even more patient. I cannot plan ahead, nor recall even this morning or yesterday, and I am so frustrated with my inability to think clearly, let alone speak properly. It is so hard to try to describe what this feels like – this endless struggle to think where I am in the flow of time, and what I am meant to be doing, let alone what I just did. Words come out in a true jumble – just rubbish at times. I don't know how Paul manages to know what I am trying to say. Handwriting is a scribble – just a muddle of letters. I can't even count money any more, and make lots of mistakes with our finances on the computer. Paul is an amazing man, keeping me trying to cope by encouraging me, and letting me do as much as possible. It is really embarrassing to be honest about this, but sometimes my struggle to cope with daily living is so overwhelming that I scream and shout, use bad language, and behave like a spoiled toddler. I am so amazed that Paul still puts up with me! Now I am also trying to take notes, track ideas and make detailed plans for my third book. There is so much to catch up with since writing the second book in 2004. It is a daunting task, but one which will exercise my brain, and keep the neuroplasticity happening. My most recent scans show quite advanced brain damage, but obviously I can still write and speak – just not very clearly sometimes! I am working hard at re-wiring my brain, all the time it is un-wiring, so it's not all downhill, but a roller-coaster ride of changes and challenges."

Christine Bryden, (2012 How am I now, www.christinebryden.com/Now.html)

The experience of living with and caring for a person with dementia

Our understanding of the experience of living with dementia has evolved over many years. Ablitt, *et al.* (2009) suggested that we have experienced a series of changes in the way the experience of dementia has been conceptualised. Initially the focus was exclusively on caring, and concentrating on the burden experienced as a consequence of caring, and the outcomes such as depression and physical ill health. During this time, the person with dementia was largely absent from research and frequently conceptualised in terms of the problems they created for family caregivers. Since the early 1990's, with the emergence of person centred care, we have moved towards a focus upon the experience for the person living with dementia (Kitwood, 1997). During this period, a wide range of literature documenting the experience of living with dementia has emerged as people have felt able to speak out. These narratives are challenging the pervasive stigma associated with dementia, so as this quote from Christine Bryden (2012) highlights, while there are considerable difficulties associated with dementia, there is also room for hope, wellbeing, maintenance of identity and continued success.

However, as Christine's quote emphasises, as well as her own determination to manage these challenges, the support of her partner Paul is fundamental to her continued wellbeing.

Narratives such as hers highlight the most recent development in our understanding, a move to considering both the person with dementia and their family members and the reciprocal influence of their relationship and dementia. This change has also required us to develop a nuanced understanding of living with dementia, recognising as Christine Bryden indicates, that this encompasses both positive and negative experiences. The journey through dementia involves considerable changes and challenges, and each family's journey is unique, for them as a whole and for each person within that family. The changes and challenges brought about by dementia require that all family members engage in

an on-going process of assimilation, adaptation and adjustment (Cheston, 2013; Keady & Nolan, 2003; Hellström, *et al*. 2007).

This section of the review therefore seeks to address the experience and impact of living with dementia for family relationships and for individuals within those relationships. Firstly the reciprocal influence of dementia and the relationships between persons living with dementia and their family members will be considered, as evidence suggests that dementia impacts upon family relationships as a whole (La Fontaine & Oyebode, 2013; Garwick, *et al*. 1994; Rolland, 1994; Allen, *et al*. 2009). Secondly, evidence concerning the impact and experience of dementia will be considered for a range of family members, including partners, adult children, grandchildren, children and young people, who in addition to being in a relationship with the person with dementia, are also involved in caregiving (La Fontaine & Oyebode, 2013; Evans & Lee, 2013; Purves, 2011; Piercy, 2007; Rolland, 1994; Allen, *et al*. 2009). Thirdly, the impact and experience of dementia for specific groups within society will be considered, as evidence suggests that aspects of their experience can be significantly different from more common caregiving/ family relationships and majority groups within the UK. Finally, the experience of service use will be briefly considered, as common themes are evident across the experience for family members who are living with dementia.

The impact of dementia upon relationships

The majority of the research considering the impact of dementia upon relationships has focused upon married couples, with other relationships considered less commonly. However, much of the research in this area has acknowledged that "The experience of giving and receiving care usually occurs in the context of a long-standing relationship which predates the onset of dementia and continues to evolve as the illness progresses" (Ablitt, *et al*. 2009: 498). This quote emphasises the importance of understanding the relational context within which dementia occurs. Rolland (1994) amongst others highlights that family

relationships are characterised by ways of relating that include:

- Having established patterns of adaptation to changing circumstances and life events;

- Emotional connectedness on a continuum of close to distant;

- Boundaries, involving who does what, where and when in given situations and how this is achieved between family members and in relation to the wider community; and

- Communication styles, including how openly family members are able to communicate on practical as well as emotional issues (Rolland, 1994, Walsh, 2006).

Rolland further suggests that chronic and life threatening conditions such as dementia, present particular psychosocial challenges to family relationships. Such challenges include:

- the length of time that people will live with the condition;

- the progressive and fluctuating nature;

- the degree and type of disability it creates; and

- the ultimate outcome and the life stage at which it occurs (Rolland, 1994).

The characteristics of families described above will all have a significant influence upon how they are able to manage and adjust to the challenges that dementia brings. Recent systematic reviews and qualitative syntheses of research have indicated a number of factors closely linked to those listed above concerning:

- the quality of the relationship between the person with dementia and their family members;

- the relationship between the person with dementia and their family members;

- the impact of dementia upon the relationship; and

- communication styles within relationships.

The quality of the relationship between the person with dementia and their family members

The quality of the relationship between family members appears to be significant in influencing the way in which adaptation and adjustment to dementia occurs. It has been found that the quality of the relationship is strongly associated with the meaning and motivation for caring for a person with dementia, and that higher levels of satisfaction with caregiving are experienced where more positive pre-caregiving and current relationships occur (Quinn, *et al*. 2012; Ablitt, *et al*. 2009).

Where current and previous relationship quality is positive, and has involved the capacity to negotiate and manage challenges; acknowledges the contributions that each party had made to the relationship; and has involved a strong emotional bond; this appears to create the foundations upon which the challenges created by dementia can be shared and 'held apart' from the relationship (La Fontaine & Oyebode, 2013; Quinn, *et al*. 2009). Strategies used included supporting the continuation of valued activities, supporting the identity of the person with dementia through overt and covert means including for example cooking with the person with dementia rather than taking over (La Fontaine & Oyebode, 2013).

Research considering the impact where the quality of the pre-existing relationship has been poor is less common, but evidence suggests that poor relationship quality may lead to conflict and disconnectedness (La Fontaine & Oyebode, 2013; Shim, *et al*. 2011). It appears possible that in this context the strategies for managing the experience of dementia may involve less positive coping strategies, including positioning the problem with the person with dementia and using deception and confrontation to manage their behaviour (Quinn, *et al*. 2009; Quinn, *et al*. 2012; La Fontaine & Oyebode, 2013; Camden, *et al*. 2011).

However, it is also important given the progressive nature of the condition, to consider the impact of dementia over time. Very few studies have considered the impact of dementia upon relationships longitudinally, or how motivations and meanings associated with caregiving might change over time (Quinn, *et al*. 2012). One of the qualitative studies that has considered this over time suggest that as the dementia progresses it may be increasingly difficult for the person with dementia to engage in actively maintaining the relationship. For some this may ultimately mean that the partner 'works alone' as 'couplehood' is no longer possible, which suggests that in some circumstances, relationship quality declines as dementia progresses (Hellstom *et al*. 2007). Furthermore, Fauth *et al*. (2012) suggest that closeness in relationships may be associated with both positive and negative outcomes for family caregivers over time, so while the closeness benefits the person with dementia, it cannot be assumed that it will be beneficial for the family member.

The impact of dementia upon the relationship

It has been identified that dementia impacts upon relationships, causing changes in opportunities for reciprocity, communication, shared activities and happiness, but that also love, emotional warmth and closeness, and affection are still possible (Ablitt, *et al*. 2009). Systematic syntheses of qualitative research have explored the impact of dementia further. Evans & Lee (2013) found that changes brought about by dementia required that married couples adapted their relationship. These changes included losses associated with companionship, shared interests, reciprocity and mutual support (Ablitt, *et al*. 2009). They found that spouses experienced loneliness and isolation as a consequence of these losses. Furthermore, couples reflected upon the change from partner to parent/child or carer/cared for, following which, the spouse who is caring takes on more of the roles that would previously be fulfilled by the person with dementia. However the manner in which this change occurred varied between couples, with some seeking to support the person with dementia to maintain such roles for as long as possible. This systematic synthesis also highlighted challenges associated with changes in intimacy. Some spouses no longer wanted intimacy

because of the change in role and some were concerned about consent, although others reported that emotional intimacy had increased as a consequence of this change.

Shifting responsibilities also required a complex process of negotiation within family relationships, which involved noticing and managing risks associated with changes in abilities and the forms of help and assistance that might be needed, whilst striving to maintain the identity of the person with dementia. The consequences of such changes included that time apart was less possible, and although time together was valued, it did appear to have negative consequences for wellbeing in some (La Fontaine & Oyebode, 2013). These consequences included conflict between the person with dementia and their family member.

In both of the qualitative syntheses identified above (Evans & Lee, 2013; La Fontaine & Oyebode, 2013), loss was identified as a consequence of dementia. Loss was seen to occur on many levels but particularly reflected loss of the relationship as it was, including the memories of a shared history, loss of a partner/ parent as they were prior to the onset of dementia and finally for some, the loss of the relationship as it was previously conceptualised. The experience of loss is complex, with some family members believing that the relationship continued to be present while others talked of moving on from the relationship and finding new friendships and relationships (Evans & Lee, 2013; La Fontaine & Oyebode, 2013).

Communication styles within relationships

As highlighted earlier, the communication styles of the family are significant in supporting families to manage the impact of dementia. Open communication appears to be necessary in order that family members are able to acknowledge the difficulties being experienced and find ways of coping, even where this involves quite painful subjects. Where one person in the relationship was not willing to engage in open communication, it appears possible that this could result in a denial of the other's experiences and feelings (La Fontaine & Oyebode, 2013).

The impact and experience of dementia upon individual family members

Evidence concerning the impact and experience of dementia for individual family members is variable, with spouse and adult children (usually daughters) being greater than studies exploring other family members. However research indicates both similarities and differences in the experience for individual family members, necessitating that their experiences and needs are considered separately.

The experience for the person living with dementia

It is necessary to consider the experience of the person living with dementia as they are part of the family relationship and as previously indicated, it is suggested that the well-being of the person living with dementia is intrinsically linked to the well-being of their family members (Burgener & Twigg, 2002; Holst & Edberg, 2011). A number of factors are considered to contribute to well-being in later life, including:

- Feeling a sense of accomplishment, self-esteem and having the personal resources to overcome challenges in life;

- Opportunities to be in relationship with others and contribute to their well-being;

- Feeling a sense of belonging in valued relationships and experiences;

- Being able to exert influence, choice and control over your own life;

- Being able to engage in meaningful activities and occupation that are motivating, stimulating and enrich your life; and

- Feeling secure and safe, financially, physically, cognitively, practically, spiritually and emotionally

(Papadopoulos *et al*. 2011).

Dementia, impacts upon well-being in particular ways, including that with the onset of dementia, people are vulnerable to their psychological defences being broken down (Brooker, 2008; Kitwood, 1997). Due to the progressive nature of the condition, dementia ultimately creates multiple physical, cognitive and functional mental health difficulties, thus people living with dementia are increasingly reliant on those in relationships with them to support them to maintain their well-being (Kitwood, 1997; Brooker, 2008; Fossey & James, 2008; Holst & Edberg, 2011).

Evidence suggests that the early experience of cognitive changes prior to and immediately following diagnosis represents a significant threat and results in distress; potential disagreement and conflict with family; fear for the future and concerns about loss of self and identity all of which impact upon well-being (Bunn, *et al.* 2012; Robinson, *et al.* 2012; Clemerson, *et al.* 2013; Steeman, *et al.* 2006). Nevertheless, following diagnosis, studies highlight that people with dementia are active in seeking to adapt to live with dementia, which includes developing practical, emotional and relational strategies (Clemerson, *et al.* 2013; Bunn, *et al.* 2012; Robertson, 2013; Steeman, *et al.* 2006).

Therefore, although changes in functioning occur from early in the experience of dementia and progress, people with a diagnosis describe the importance of remaining independent and actively seeking ways of adapting to the difficulties, demonstrating the continued importance of a sense of agency and control over one's life and maintaining valued activities and occupation (Beard, *et al.* 2009; Cahill, *et al.* 2007; Steeman, *et al.* 2006). However, studies also suggest that well-being can decline as dementia progresses, as a consequence of increasing dependence and difficulties with cognitive function (Holst & Edberg, 2011). This research suggests that decreases in wellbeing correspond with increases in stress and distress experienced by their family caregivers. Thus interventions which involve improving the well-being of people living with dementia alongside their family caregivers is likely to be an important factor influencing outcomes (Ablitt, *et al.* 2010; Holst & Edberg, 2011).

Spouse/ Partners

The experience of spouses/ partners of caregiving for a partner with dementia are intrinsically related to the relationship in which caregiving takes place. Much of the literature described earlier, concerning the impact of dementia upon relationships, reflects the experience of spouses/ partners as it is these relationships that have predominantly been studied. Spouse care often occurs in the context of a longstanding relationship, characterised by degrees of commitment, satisfaction, concordance in emotional or physical well-being and sharing of roles (Walker & Luszcz, 2009). Furthermore, Walker and Luszcz (2009) indicate that the spousal relationship has the potential to either protect or increase the risk of poor mental health outcomes (p474) and that the presence of ill-health in one spouse may create ill-health in the other, although they suggest that marital closeness may mediate this outcome.

Caregiving in the context of a spousal relationship/ partnership is often not considered as caring by spouses, rather, caring activities are more likely to be associated with the bonds and the commitment that couples make to each other (Camden, *et al.* 2011; Hellström, *et al.* 2007; Barnes, *et al.* 2013; Davies, 2011). Consequently, when a spouse requires support, their partner may gradually take on extended roles which may not be considered to be out of context of their relationship (Hellström, *et al.* 2007). Nevertheless, when spouses provide care to a partner with dementia, research suggests that they are likely to invest considerable energy in maintaining the self-esteem and identity of the partner who is living with dementia and that on occasions, this investment may be to the detriment of their own well-being (Perry & O'Connor, 2002; Savundranayagam, *et al.* 2011).

The gender differences in spouse care also need to be acknowledged. It is suggested that female spouse caregivers may experience greater levels of stress and burden as a consequence of caregiving than male spouse caregivers. This is thought to be because male caregivers are more likely to use coping strategies such as problem solving, treating caregiving roles as 'work' and therefore are less emotionally involved and experience less distress.

(Pöysti, *et al*. 2012; McDonnell & Ryan, 2011). Conversely, women are more likely to be emotion-focused in their coping and therefore have significant emotional investment in caregiving (McDonnell & Ryan, 2011). It is also suggested that the need for assistance varies between men and women, with women more likely to attend support groups, whereas men are less likely to avail themselves of such support, unless it is framed as information and skills development (McDonnell & Ryan, 2011).

The impact of caregiving for spouse partners is known to be significant, and includes a range of psychological, physical and social outcomes including high levels of depression and loneliness, and stress (Shim, *et al*. 2012). Such outcomes arise from an interplay of factors including:

• the quality of the previous and current relationship;

• the motivations and meanings associated with caregiving;

• the coping strategies used by spouses to manage the challenges brought about by dementia;

• the losses associated with dementia;

• the behaviour of the person with dementia;

• the supportiveness of family and social networks; and

• the health and well-being of the person with dementia and the spouse caregiver (Holst & Edberg, 2011; Savundranayagam, *et al*. 2011; Quinn, *et al*. 2012; Davis, *et al*. 2011; Gallagher-Thompson, *et al*. 2012; Mausbach, *et al*. 2012; Ducharme, *et al*. 2012).

Spouse caregivers are also known to be less willing to accept formal help such as day care, use it at later stage and gain less benefit from it and also to consider institutional care as a last resort (Pöysti, *et al*. 2012; Gallagher, *et al*. 2011b; Kim, *et al*. 2012). It is also evident that spouses can experience satisfactions in providing care derived from their on-going relationship

with their spouse, shared intimacy and love (Shim, *et al*. 2012; Hellström, *et al*. 2007).

Additionally, although some spouses highlight ambivalence in their relationships and caring role with the person with dementia, they nevertheless were able to identify satisfactions from specific uplifting events, such as shared meaningful activities (Shim, *et al*. 2012). Therefore, while it is identified that spouse caregivers may be at risk of negative outcomes, this needs to be understood within the relational context in which caregiving takes place. Such contextual factors include that:

• The motivations and meanings associated with caregiving may result in spouses not identifying themselves as a caregiver;

• Spouse caregivers may experience considerable satisfactions in their relationship; and

• Spouses may be unwilling to accept formal services to support them in their role, even where their own well-being might be compromised.

Consequently, spouses may benefit from interventions that address the relational context and the stressors experienced which may impact upon individual and couple well-being, as well as the more traditional interventions associated with dementia caregiving, such as psycho- education and skills building.

Adult Children

Daughters are identified as the most common caregivers for people living with dementia after a spouse, with social norms having a significant influence upon their involvement in caregiving roles (Quinn, *et al*. 2010; Alzheimer's Society, 2011). However, while female, adult child caregiving continues to make up the greater proportion of caregiving for people with dementia, with the changing roles of men and women in society, it has been suggested that there is an increasing trend towards sons' involvement in caregiving (McDonnell & Ryan, 2011).

Furthermore, children-in-law are also recognised to provide care (Pinquart & Sorenson, 2011). Adult child caregivers are characterised by significant differences to spousal caregiving, including that they are much more likely to live separately to the person with dementia and have additional responsibilities including child rearing, employment and other family relationships (Alzheimer's Society, 2011; Pinquart & Sorenson, 2011).

Relationships between parents and adult children are multidimensional, involving varying degrees of expectations concerning independence/interdependence according to family, cultural and societal norms, all of which will influence the caregiving experience (Dykstra & Fokkema, 2011). Providing care for a parent is likely to involve considerable renegotiation of existing roles and norms within relationships with the parent and others in the adult child's life. Such renegotiation can bring past conflicts and ambivalent feelings to the surface, as well as providing opportunities for reciprocity and continued expression of commitment (Piercy, 2007; Ward-Griffin, *et al.* 2007; Sechrist, *et al.* 2012; McDonnell & Ryan, 2012).

Research indicates that the motivations for caregiving for adult children include; a desire to reciprocate for past care; the closeness of the current relationship; a sense of duty and responsibility; proximity to the person with dementia; and other sibling involvement in caregiving (Camden, *et al.* 2011; McDonnell & Ryan, 2011; McDonnell & Ryan, 2013; Ward-Griffin, *et al.* 2007; Piercy, 2007).

The quality of the previous relationship between adult children and their parents is important, influencing the quality of the current relationship and consequently outcomes for the adult child and their parent (Ward-Griffin, *et al.* 2007; Piercy, 2007; McDonnell & Ryan, 2012; Fauth, *et al.* 2012). As mentioned earlier, there is evidence of continued positive relationships as well as relationships characterised by conflict (Ward-Griffin, *et al.* 2007; McDonnell & Ryan, 2012).

The impact of caregiving on adult children is known to be significant. Research indicates that they experience stress arising from their interpretation of the activities

of caregiving, resulting in the risk of negative outcomes including poor self-rated health (Kwak, *et al.* 2012; Fauth, *et al.* 2012; Savundranayagam, *et al.* 2010). Changes in the relationship are associated with a greater risk of placing the person with dementia in a care home, as are difficult behaviours (Savundranayagam, *et al.* 2010). Furthermore, adult child caregiving is associated with greater levels of family conflict, as it is suggested that while adult children are more likely to expect help from kin, negotiations may result in disagreements about level of involvement (Kwak, *et al.* 2012). Adult children also experience emotional burden, social isolation and job strain as a result of caregiving demands, as well as physical and psychological symptoms such as depression (Pinquart & Sorenson, 2011). Adult children are more likely than spouses to use services such as respite and day care, and to gain benefit from such interventions (Decaporale, *et al.* 2013; Kim, *et al.* 2011) They are also more likely to consider institutional care for the person with dementia, particularly in the context of changes in the behaviour of the person with dementia and in their relationship (Gallagher, *et al.* 2011b).

Studies have only recently begun to explore the differences in experiences for sons as caregivers of parents. Such research challenges existing beliefs that men are less capable than women in providing care, and also highlight differences in coping styles between men and women, with one qualitative study suggesting that men may engage a 'rational' approach to their caregiving, within which they were possibly more realistic about what they could achieve (McDonnell & Ryan, 2013).

In summary, research evidence identifies that adult child caregivers experience negative outcomes, although as with spouses, this needs to be viewed in the context of possible satisfactions too, with some studies identifying positive motivations for caregiving and continued positive relationships (Ward-Griffin, *et al.* 2007; Piercy, 2007; McDonnell & Ryan, 2013). However, studies suggest that the experience and outcomes are different for adult children, and are influenced by the different circumstances and relational context in which caregiving takes place. Consequently, interventions for children need to acknowledge these different contexts and recognise

that they may require and benefit from different forms of intervention to spouse caregivers (Pinquart & Sorenson, 2011).

Young people and children (including grandchildren)

The needs of children and young people in families with a grandparent, or less commonly a parent with a diagnosis of dementia have only recently been considered within research.

Research has largely focused upon adult family members in primary caregiving roles; however a number of recent studies have identified that children and young people will be affected psychologically and developmentally. This is particularly true if they are living with the person with dementia (Hamil, 2012; Nichols, *et al*. 2012; Celdrán, *et al*. 2011; Celdrán, *et al*. 2012; Denny, *et al*. 2012; Gelman & Greer, 2011). The impact of dementia upon children and young people relates to their developmental needs when coping with dementia in a parent or grandparent. Children and young people will face many normal life transitions, including education, moving out of the parental home and work and the family relationships that they have are important factors in influencing the success of these transitions (Ross, *et al*. 2005). Therefore when considering the forms of interventions required by family caregivers, it is also important to consider the needs of children and young people.

Having a grandparent with dementia

Relationships between grandparents and their grandchildren are known to provide considerable benefits (Ross, *et al*. 2005). While the onset of the need for care in a grandparent is likely to be a normal transition in the life of a young person, it will nevertheless create significant challenges (Ross, *et al*. 2005). These challenges include the impact of dementia upon the grandparent and the role of the grandparent without dementia and their parents in providing this care, particularly where care needs involve considerable time commitments (Celdrán, *et al*. 2011; Celdrán, *et al*. 2012; Hamil, 2012). Evidence suggests that parents influence strongly the relationship between children and their grandparents, consequently parental involvement in caregiving can impact both positively and negatively depending upon the strategies used by parents to support the relationship, including communication styles, providing information about the disease and supporting the child to understand what is happening (Celdrán, *et al*. 2011; Hamil, 2012). Having a grandparent with dementia can result in positive experiences including generating a greater sense of social responsibility and gaining satisfaction in being involved in supporting the grandparent (Celdrán, *et al*. 2011). However, negative experiences are also evident and include feelings of loss and sadness; difficulties in their experience of the behaviours of the person with dementia, including feelings of anger and frustration; and finally feelings of guilt (Celdrán, *et al*. 2011; Hamil, 2012).

Having a parent with dementia

In comparison, the experience of having a parent with dementia is a relatively uncommon experience. Nevertheless where this does occur, it presents particular challenges for children and young people, given the relatively low level of service provision for younger people with dementia and that children and young people are recognised as hidden carers (Svanberg, *et al*. 2010). The experience for children and young people of a parent with dementia can generate similar challenges to those identified for grandparents above, including experiences of changes in relationships, loss and frustration (Svanberg, *et al*. 2010; Gelman & Greer, 2011; Denny, *et al*. 2012). However the impact of having a parent with dementia additionally involves fundamental changes in the relationship between child and parent, with some studies identifying that children and young people experience a degree of detachment and subsequently role reversal (Svanberg, *et al*. 2010; Denny, *et al*. 2012). While benefits include an increasing maturity, it is nevertheless evident that such experiences can also generate considerable losses. Furthermore the impact upon school life can be considerable, including intolerance of school friends and embarrassment arising from the behaviour of the person with dementia (Nichols, *et al*. 2012; Denny, *et al*. 2012).

When considering the involvement of children and young people in caregiving, it is necessary to recognise that research indicates that they are unlikely to have the cognitive functions and resources required to cope with caregiving stressors and manage their own needs (Hamil, 2012). Evidence suggests that children and young people are actively involved in supporting their grandparents and parents when they have a diagnosis of dementia, although they may not necessarily see themselves as caregivers. Involvement in caregiving occurs for a number of reasons including; parental involvement in caregiving; particularly where parents were providing a greater number of hours of support; where the previous relationship was positive; because of the love they have for the person with dementia and through choice (Hamil, 2012; Denny, *et al.* 2012; Svanberg, *et al.* 2010; Celdrán, *et al.* 2011). The nature of the support offered varies but is suggested to include; physical support such as with feeding and mobility; help with household chores including meal preparation; communication with health care professionals, and personal assistance including medication administration (Nichols, 2012; Hamil, 2012; Svanberg, *et al.* 2010; Denny, *et al.* 2012; Celdrán, *et al.* 2011). However such involvement in caregiving is found to have considerable costs including high levels of stress and burden (Svanberg, *et al.* 2010). Furthermore, Denny *et al.* (2012) highlight research from other conditions demonstrating the difficulties for children in being exposed to a parents' deteriorating condition and suggest that it is important to recognise the considerable costs for children in being involved.

It is therefore suggested that the needs of children and young people where a family member has dementia should be recognised and support should be offered that is specific to their needs. This includes supporting family members to openly communicate with children; providing tailored information and education concerning dementia; developing psychological interventions including peer support; assisting the development of a different relationship with the parent or grandparent with dementia and providing family interventions (Svanberg *et al.* 2010,; Denny, *et al.* 2012; Gelman & Greer, 2012).

Limitations

It should be acknowledged that there are some limitations in the research reviewed above.

- Firstly, the research evidence largely reflects relationships within traditional family structures, and predominantly spouses. However family relationships and caring is affected by a range of factors including ethnicity, sexual orientation, gender, disability and divorce.

- Secondly, much of the research has focused upon people with a diagnosis of Alzheimer's disease or dementia without diagnosis of subtype.

Thus this next section considers available research evidence for the impact and experience for different groups within society. The impact of less common forms of dementia will be considered later in the review.

'Evidence suggests that children and young people are actively involved in supporting their grandparents and parents when they have a diagnosis of dementia, although they may not necessarily see themselves as caregivers.'

The impact of caregiving for particular groups within society

Caregiving within migrant and minority communities

It is increasingly recognised that ethnic background has an influence on a person's perception of dementia, caregiving experiences, and use of formal support services (Gerdner, *et al.* 2007; Marano & King, 2010). Recent research has revealed estimates of nearly 25,000 people currently living with dementia from BAME communities; 50,000 by 2026 and 172,000 by 2051 in correlation with the growing and ageing UK BAME population living in England and Wales (All Party Parliamentary Group, 2013). In 2001 approximately 532,000 people from BAME groups were aged 65 years and over. This figure is expected to rise to approximately 3.8 million by 2051 (Lievesley, 2010) whereby significant proportions of people from BAME communities will be aged 65 years and over when compared to White British people – in particular those from Black Caribbean and Asian Indian communities (Wohland, *et al.* 2010). Early onset dementia and vascular dementia are most prevalent in these communities due to higher incidences of hypertension and diabetes (Seabrooke & Milne, 2004; Ahtiluoto, *et al.* 2010; All Party Parliamentary Group, 2013).

The Department of Health (2005) refer to black and minority groups as *'all people of minority ethnic status in England. It does not only refer to skin colour but to people of all groups who may experience discrimination and disadvantage, such as those of Irish origin, those of Mediterranean origin and Eastern European migrants'* (p.11). Due to the heterogeneity of such communities, it is difficult to draw generalisations for such a diverse group of people, for there are differences both within and between communities and individuals (Mackenzie, 2007; Shah, 2007; Bhattacharyya & Benbow, 2012). The negative connotation of 'discrimination and disadvantage' is derived from the social and political influences on their lives as migrants. For the purpose of clarity, we refer to such groups as migrant and minority communities including indigenous people born to migrant parents.

An increase in the number of older migrant and minority people in the UK is likely to lead to an increased need for dementia services yet; they are currently under-represented in dementia services (Moriarty, *et al.* 2011). In 1998, the Social Services Inspectorate published the report *'They look after their own, don't they?'* The report, based upon inspectorial evidence, challenged the myth that minority ethnic families, particularly Asians, universally support dependent members and, instead, highlighted a number of service deficits affecting minority ethnic communities (DH 1998). Since this report, the widespread assumption that Asian people all live in extended families with tight kinship networks has continued to be questioned. The evidence increasingly shows that kinship patterns of help are changing with the rise in the numbers of nuclear families and younger adults moving away to work (Moriarty & Webb, 2000). There are additional challenges for migrant and minority carers of a family member with dementia associated with culture and community norms, and the stigma of mental health (Jutlla, 2013).

Whilst there is evidence of ethnic minority families becoming more fragmented and nuclear (Moriarty & Webb, 2000), care is still largely negotiated between family members based on their positions, their expertise, availability and what the person with dementia requires (Jutlla, 2011). The family as a resource is particularly important to those who are either not recognised by services, or lack knowledge of the services available to them (Jutlla & Moreland, 2007; Jutlla, 2011; Jutlla, 2015; All Party Parliamentary Group, 2013).

Spousal/ Marital Relationships

The difficulties of role reversal and taking on additional responsibilities for Asian older women caring for their husband with dementia has been noted (Moreland, 2001). Research with Sikh carers of a family member with dementia in Wolverhampton in the UK, highlighted the impact of migration on such experiences (Jutlla, 2011). Due to social isolation post migration, older Sikh women struggled with tasks that involved being out in the public domain such as grocery shopping and paying household bills. Whilst older women often perceive themselves as

isolated (Mand, 2006), they relied heavily on their children to provide support with caring for their spouse with dementia (Jutlla, 2011).

Research on male carers tends to focus less on the positive aspects of care and more on the difficulties they experience when taking on caring responsibilities (Ribeiro & Paul, 2008).

However, the migration experiences of Sikh older men in Wolverhampton contributed to supporting caring activities later in life (Jutlla, 2011; Jutlla 2015). Having migrated to the UK prior to sending for their wives, migrant men acquired domestic skills to live independently which they were then able to transfer to their caring situations (Jutlla, 2011). Indications of resiliency as suggested by their high levels of self-efficacy and problem solving abilities have too been reported in migrant carers of a person with dementia in the United States (Jason, 2010; Clay, *et al*. 2010).

In addition to gender and generation identities (Mand, 2006), social capital as an available resource is also dependent upon their class identity both prior and post migration with those from middle class backgrounds having the advantages of being educated and having English language skills (Jutlla, 2011). The majority of older migrants in the UK will have migrated from working class backgrounds causing additional language barriers due their non English speaking ability and common literacy problems (Jutlla, 2013). While education levels can be an important factor for the ways in which services are negotiated by migrant carers (Karim, *et al*. 2011), there are still implications for British educated, or British born ethnic minority people caring for a family member with dementia.

Intergenerational Relationships

Although cultural norms associated with gendered roles and positions in the family are a universal concept relevant to all communities, research with Sikh carers of a family member with dementia made evident the expectations to adhere to such norms by their community, especially for intergenerational carers

(Jutlla, 2011). A study by Kane and Houston-Vega (2004) found intergenerational conflict in Chinese Americans whose parents expect to be cared for in their later years by their eldest son and his wife or another child. Similar to the findings of this study, Sikh intergenerational carers reported conflict between their desires to meet individual needs versus their family's needs as a result of cultural and community norms that children should care for their elders (Jutlla, 2011; Jutlla, 2015). Not only did this lead to feelings of ambivalence towards such community norms, but also feelings of isolation and depression – particularly for the women (Jutlla, 2011; Jutlla 2015). Other research on informal care in Asian families has too highlighted the potential for Asian women to feel trapped and powerless due to norms about gendered roles in their communities (Mand, 2006).

Caregiving for younger people with dementia

Only a small amount of qualitative and quantitative research explores the experience of dementia for younger families, and much of this is cross sectional, therefore it is difficult to identify how dementia is experienced over time (van Vliet, *et al*. 2010). Research exploring the impact of dementia on younger couples and families highlights that caregiving in this context involve considerable challenges associated with the life stage at which the illness occurs. This includes managing responsibilities such as mortgage, work and other practical considerations as well as familial responsibilities including dependent children (Bakker, *et al*. 2010; Lockeridge & Simpson, 2012; van Vliet, *et al*. 2010). Studies suggest that caregivers of younger people with dementia experience feelings of frustration, grief or guilt, loneliness or social isolation and poor emotional well-being, with female caregivers appearing to be at greatest risk of negative psychological impact and spouse caregivers experiencing greater levels of loneliness (van Vliet, *et al*. 2010). Furthermore, this systematic review highlighted that difficulties were experienced in relation to the intimate aspects of the relationship and in forming new relationships. Roach, *et al*. (2014) used narrative analysis to identify 5 recurring storylines used by families experiencing young onset dementia at different points in their journey: agreeing; colluding; conflicting; fabricating; and protecting. Families that primarily

adopted an 'agreeing' storyline were more likely to face challenges positively, whereas those who assumed largely 'conflicting' and 'colluding' storylines were more likely to need help to adapt.

A few qualitative studies have explored the experience for younger spouse caregivers. One has found that spouse caregivers experienced difficulties in accepting that dementia might be a cause of the difficulties and considerable feelings of stigma associated with the condition, particularly when faced with services which were not tailored to their partners needs and were not responsive to the specific difficulties that were frequently faced (Lockeridge & Simpson, 2012). Stokes *et al* (2014) re-emphasized that a lack of information; personal understanding and continued support resulted in caring partners having difficulty in understanding and adjusting to behavioural, physical and psychological changes in their partner.

Furthermore, as younger people with dementia experience less common forms of dementia, difficulties experienced by caregivers can be compounded by the particular challenges associated with these forms of dementia. Such difficulties included the symptoms associated with such conditions as fvFTD, such as loss of inhibitions and socially embarrassing behaviours, as well as fundamental changes in relationships (Oyebode, *et al*. 2013).

van Vliet *et al*. (2010) summarise their review by suggesting that family caregivers of younger people with dementia experience high levels of burden and experience depression.

Furthermore, that they also experience difficulties including family conflict, delays in diagnosis, and competing demands associated with the life stage at which the dementia occurs.

Experience of LGBT people

There is limited evidence on the experience and needs of lesbian, gay and bisexual and trans (LGBT) carers. This may be because research tools are not sufficiently sensitive to the LGBT experience or that LGBT carers are reluctant to disclose their orientation, possibly fearing discrimination, and are therefore underrepresented in the literature. Institutionalized homophobia is also posited as an explanation (Price, 2008). UK policy particularly in the last ten years has attempted to secure legal recognition and protection for lesbian, gay and bisexual people through the Civil Partnership Act (2005), the Equality Act (Sexual Orientation) Regulations (2007), The Equality Act (2006) and The Equality Act (2010). However there is a growing recognition that LGBT people with dementia and their needs remain underrepresented in dementia services and in the strategic development of dementia support (Alzheimer's Society, 2013; Westwood, 2014: Peel & McDaid, 2015). The LGB population is estimated between 7.5% and 10% of the total population (Aspinall, 2009) and it is suggested that this may be an underestimate. Estimates of the trans population in the UK vary widely from 65,000 to 300,000, however there is no official estimate (Office of National Statistics, 2009).

LGBT people have a range of relationship forms which may not follow typical heterosexual patterns. For example, their relationships and their families may be more strongly based on "choice" rather than blood ties (Peel & McDaid, 2015).

It is important to note that the LGBT communities are complex with varied experience and needs, not a heterogeneous single community. They are likely to have experience of stigma, discrimination and marginalisation in common, and many older people are likely to have vividly embedded memories of times "pre Stonewall" when they were compelled to conceal their sexuality with the resultant emotional and psychological stress, which may also have impacted on their engagement with the wider world. Baby boomers and younger LGBT people on the other hand, whilst still experiencing prejudice and discrimination, may have felt greater empowerment throughout their life course. In situations where either the person with dementia, their carer or both are in an LGBT relationship it is suggested that they experience triple jeopardy on account of their LGBT identity, cognitive impairment, and ageing (McGovern, 2014).

Privacy is often a learned or preferred strategy. However Age UK (2015) suggest that LGBT people looking after a partner can feel pressure to 'come out' about the nature of their relationship (or conversely the need to go to elaborate lengths to hide their relationship) when they encounter professionals involved in their care. Either approach may create great additional distress for LGBT carers. The evidence in respect of LGBT people's experience of health and social care is inconclusive, both for themselves or those they care for. In Heaphy, *et al.*'s (2003) research only 35% of respondents felt health professionals were likely to be positive towards gay and lesbian service users, whereas in the Help and Care (2006) report 79.1% of respondents said that they had not experienced negative responses to their sexuality from public services or voluntary organisations. Three factors in particular have been shown to deter older LGBT people from engaging with healthcare providers: they are wary of a system which presumes everyone has a heterosexual identity and relationships; they perceive the system to operate on an assumption that heterosexual identity is superior; and thirdly they fear prejudice and discrimination based on their sexuality/sexual identity (Ward, Pugh, & Price, 2011). Willis, *et al.* (2011) found LGBT carers encountered heterosexist responses and heteronormative assumptions from health and social care professionals, in one example to the point where a partner faced exclusion from service.

In interviews with gay and lesbian women carers Price (2010) found that some of the women were concerned that negative stereotypes would influence the assessment and ultimately the type of care LGBT people received. Westwood (2014) in her work on lesbian and bisexual women found that some chose to hide their sexuality, life story or significant relationships because they feared discrimination.

For many carers the reactions of professionals to disclosure of sexuality were critical and influenced their experience of receiving care. The responses reported in a variety of studies could best be described as a broad acceptance of LGBT people's circumstances but without acknowledgement of any specific needs they may have (Price, 2010; Willis, *et al.* 2011; Ward, Pugh & Price, 2011)

Price (2010) reported that carers, having seen services struggle to provide person-centred support to the people they were caring for (most of whom were heterosexual), expressed fear that the care and support they themselves might receive as a member of a sexual minority. These fears included facing negative reactions to their sexuality, being forced 'out', losing contact with gay and lesbian friends and family, losing control of their own lives, isolation and marginalisation. Overall, they felt it unlikely that their sexuality would be respected or supported. Loss of self in the person being cared for due to the progressive loss of memories, an impaired capacity to create new meanings and continuing narrative of their relationship is a common concern for members of the LGBT community (McGovern, 2010).

Caregiving for people with Learning Disabilities and Dementia

The increased risk of AD in people living with Down's syndrome (DS) due to genetic risk factors is widely recognised (Aisen, *et al.* 2005; Zigman & Lott 2007). The onset of Alzheimer's disease and other subtypes begins at an early age in people with Down's syndrome, in the fifth and sixth decades of life, with the average age of onset being mid 50's (Strydom, *et al.* 2010; British Psychological Society & Royal College of Psychiatrists, 2015). In recent years it is also recognised that as people are living with learning disabilities into older age, the prevalence of dementia among this population has also increased (Strydom, *et al.* 2007; Strydom, *et al.* 2009; Whitwham & McBrian, 2011).

Limited research exists on the family experience of caring for a person with a learning disability and a diagnosis of dementia and much of it is qualitative, thus limiting transferability. However one such study describes the particular challenges faced by the families in their study, which included:

• a lack of knowledge in family members about the possibility of their family member developing dementia;

• the lack of support networks available to support families in this position;

- families' lack of knowledge about the networks that exist; and

- difficulties in diagnosis due to the differences in initial symptom experience (Carling- Jenkins, *et al*. 2012).

These findings are supported by a more recent qualitative study by Perera & Standen (2014) in which carers sought to make sense of their caring role by developing a narrative both of the person's life and also of their own relationship and caring responsibilities.

McLaughlin (2010) found that lone carers in particular expressed a desire to talk with others in the same situation but did not believe that this was possible.

Furthermore, it has also been identified that families experience considerable emotional challenges in such circumstances, as the diagnosis of dementia represents a further significant loss when a person has already lived with a learning disability (RCP & BPS, 2009). The diagnosis of dementia may come at a time when family carers themselves need more support due to their own changing health or ageing (BPS&RCP, 2015).

It is therefore suggested that family members may experience stress and confusion as they try to cope with the challenges brought about by the additional diagnosis of dementia as well as the challenges of negotiating service systems which are poorly equipped to meet their needs (Carling-Jenkins, *et al*. 2012). Further research is however required to fully understand the experiences and needs of families living with learning disabilities and dementia.

Experience of Service Use

Within the UK, the experience of family members who are living with dementia is widely understood to be variable, with many family members reporting significant challenges in accessing services which are appropriate to their needs and the needs of the person living with dementia (Department of Health, 2009; Alzheimer's Society, 2012; Newbronner, *et al*. 2013).

Reports such as these highlight that such challenges begin at the point of suspicion that something is wrong, and continue throughout their journey with dementia, and are influenced by such factors as age, ethnicity, sexual orientation, gender and living situation. These difficulties are influenced by a range of factors including:

- Knowledge and attitudes of the general public;

- Knowledge and attitudes of professionals;

- Beliefs about dementia, influenced by lack of understanding and stigma, absence of the concept within specific cultures, attribution of symptoms to normal ageing, or other health difficulties;

- Denial; and

- Lack of co-ordination within and between service systems

  (All Party Parliamentary Group, 2012; Manthorpe, *et al*. 2011).

Evidence from consultations with people living with dementia and their family members have emphasised the considerable variability in what people believe they need, but core themes about services can be drawn from such research. These themes include:

- People living with dementia and their families want support to enable the person living with dementia to remain at home as far as this is possible;

- People value early assessment and diagnosis and a significant proportion of people wish to know their diagnosis;

- Following diagnosis, people identify the need for individualised and tailored information and education about dementia, available in a variety of forms and accessible throughout the journey with dementia;

- An ongoing point of contact through the journey with dementia;

- There are a number of critical points in the journey with dementia which present key opportunities for targeted information, signposting and support;

- Access to appropriate treatment and support when this is needed; and

- Interventions that are responsive to their particular circumstances and needs

(Department of Health, 2009; Robinson, *et al*. 2011; Alzheimer's Society, 2012; Newbronner, *et al*. 2013).

Thus when designing interventions for family members living with dementia, it is important to take account of the views expressed concerning the challenges associated with variability of existing service provision and the level of understanding, knowledge and services required by people living with dementia and their families.

Neville *et al*. (2015) Literature review: use of respite by carers of people with dementia

This review explored the impact of respite care and sought to establish its place in maintaining people in their home. It reviewed seventy six studies undertaken between 1990 and 2012.

Themes included: information access; barriers to carers seeking respite; satisfaction and outcomes of respite; the characteristics of effective respite. Respite services across different countries differed in respect of availability, programmes, hours of operation, convenience, staff numbers and training and particularly different levels of funding. Models of respite where the person stayed at home and respite in a care setting were included. RCTs which have shown that day centres lead to decreased carer stress and burden were acknowledged.

It considered home based respite and breaks away from the home. It found potential for both respite models to complement each other in providing better health outcomes for carers and people with dementia. The authors suggested that home respite may be better used if carers have access to counsellors or support groups

to help them find strategies to make the most of "stolen moments" or worry- free care. Separate respite might be enhanced by a thorough assessment of the needs of the person and their carer and the provision of respite tailored to the assessed needs. Respite needed to be positive for both to counter feelings of "failure" or "guilt". The review identified the potential for respite to work cyclically with home respite benefiting from additional respite away from home. It also identified that external respite services created space from their caring role which strengthened carers resilience and enabled them to address own health needs and if respite was proactive in ensuring comfort and safety of the person with dementia this was both positive for the person and allayed carer anxiety.

The review found it difficult to form definite conclusions about the use of respite care by carers. Despite potential benefits the uptake by carers of people with dementia was relatively low. Three reasons were identified for poor uptake: inadequate access to information, Information overload and limited referrals by GPs.

This review concluded that, the potential of respite will only be effective and well used if it is designed to deliver what carers feel is right for them and the person with dementia.

'It is important to take account of the views expressed concerning the challenges associated with variability of existing service provision and the level of understanding, knowledge and services required by people living with dementia and their families.'

What implications does caregiving have for the person/family member involved in caregiving and the person with dementia?

There are a number of known outcomes related to family caregiving. These outcomes can be summarised in six main areas;

1 Deterioration in the physical health of the family caregiver, including increased consultation with health care professionals and neglect of own physical health (Van Mierlo, *et al.* 2011; Tremont, 2011); an increase in physical ill-health such as higher levels of cardio-vascular disease (Wang & Chien, 2011); reduced immune functioning (Wang & Chien, 2011; Tremont, 2011); increased use of medication (Wang & Chien, 2011); increased risk of developing dementia (Norton, *et al.* 2010) and an increased risk of mortality, (Schulz & Beach, 1999; Christakis & Allison, 2006).

2 Deterioration in the psychological wellbeing of the family caregiver, including lowered quality of life and wellbeing (Sorensen, *et al.* 2006) ; prolonged stress (Williams, *et al.* 2010); increased levels of depression and anxiety (Wang & Chien, 2011; Tremont, 2011; Schulz & Martire, 2004) and increased risk of prolonged grief responses (Tuya Fulton & Epstein-Lebow, 2011).

3 The psychosocial consequences of caregiving include social isolation and changes in social relationships (Van Mierlo, *et al.* 2011) and changes in the relationship quality between the persons giving and receiving care (Quinn, *et al.* 2012).

4 Admission to institutional care (Tremont, 2011; Spijker, *et al.* 2008; Gallagher-Thompson, *et al.* 2012).

5 Abuse (Cooper, *et al.* 2010; Wiglesworth, *et al.* 2010; Camden, *et al.* 2011).

6 The financial impact of caregiving, including having to leave employment as a consequence of caregiving responsibilities (Beinart, *et al.* 2012: Nunneman, *et al.* 2012).

Factors that protect or increase the risk of poor outcomes in caregiving

This next section considers the factors that protect or increase the risk of poor outcomes. Firstly the theoretical models that are predominantly used to inform our understanding of the experience and impact of caregiving will be reviewed. Secondly, the factors that are known to influence outcomes will be discussed. Thirdly, evidence concerning those family caregivers who are known to be most at risk of poor outcomes is reviewed. Finally, the assessment processes required to identify the needs of family caregivers prior to interventions will briefly be summarised.

Research concerning the outcomes of family caregiving, the factors contributing to these outcomes and the development of interventions designed to prevent such outcomes has largely been influenced by theoretical models concerning the experience and impact of stress, in particular the Stress Process Model (Pearlin, *et al.* 1990) and the transactional model of stress and coping (Morrissey, *et al.* 1990). The stress process model indicates that five main components should be considered when understanding the experience of stress for family members in caregiving roles. These include:

• The caregiving context. The context of caregiving involves considering socio- demographic factors such as age, education, gender and employment. Additionally, this includes the intensity of involvement the family member has in caregiving and perhaps most importantly, their relationship to the person living with dementia.

• Primary Stressors. Primary stressors are divided into two aspects; the objective difficulties experienced as a consequence of the illness, for example changes in activities of daily living or behaviours and the subjective experience of these stressors. Interventions should be based upon those stressors identified as problematic by the family member involved in caregiving rather than what might objectively be considered as stressful.

- Secondary Stressors. Secondary stressors are not less important but rather are related to the way in which caregiving impacts upon other aspects of the family member's life, for example creating conflict in other relationships or difficulties with employment. Also in the way that caregiving impacts upon self-concept and self-esteem. Pearlin *et al*. (1990) terms these role strains and intra-psychic strains.

- Resources. This involves the intrapersonal and interpersonal resources that the person may have to assist them in coping with their caregiving role and include coping strategies and social support. Social support includes other family members and relationships and also formal support services.

- The fifth factor in this model is the outcome of caregiving, involving impacts upon the health of the family caregiver, their emotional wellbeing and the placement of the person living with dementia in institutional care.

Elvish, *et al*. (2012) indicated that the model suggests interplay between objective factors such as the behaviour of the person with dementia, and subjective factors such as the family caregiver's feelings concerning their role that would predict specific outcomes.

The transactional model of stress and coping views outcomes as arising from interplay between the person and the particular situation they are confronted with. Stress arises when the person appraises the situation and is either not able to identify coping resources to address the situation, or their coping resources are ineffective (Elvish, *et al*. 2012). They further suggest that the crucial issue is not the situation itself, but how the person appraises this event. They suggest that this model is helpful because it accounts for differences in caregiving reactions to similar events.

Both of these theoretical models can be considered to be a useful framework for considering the factors influencing outcomes in caregiving, and a considerable body of research has focused upon the factors leading to those outcomes. Until recently, research has rarely

addressed those factors that may be protective. However evidence is increasing and suggests that protective factors such as self-efficacy are important (Gallagher, *et al*. 2011a; Gallagher, *et al*. 2011b; Beinart, *et al*. 2012).

Thus it is necessary to consider those factors that might lead to negative outcomes but also to identify those that may serve to protect against such outcomes occurring. However, the identification of risk and protective factors is a complex undertaking. Zarit, *et al*. (2010) carried out a study to explore the associations between risk factors and outcomes, in a sample of 67 caregivers caring for a family member in the middle stages of dementia. They grouped 15 risk factors into three groups:

- risks related to demands on the caregiver's time;

- risks related to the spillover of care demands into other areas of the person's life, including roles, relationships, and activities − e.g. loss of relationships, family conflict, health behaviour issues, dissatisfaction with informal help; and

- risks associated with low use of supportive services and barriers to using help − dissatisfaction with formal help, financial strain.

They used six outcome measures: Role overload, Role captivity, Depressive symptoms, Anger, Positive affect and Subjective health. They found that there was little evidence of correlation among risk factors. In the main, the patterns of risk were unique to each family caregiver, with different combinations of risk factors associated with each outcome measure. Where outcome measures were used, these showed higher correlations with one another, but were still variable in the number and type of outcomes that were elevated. An association between the caregiver's health behaviour and stress-related outcomes was identified, but this could occur either positively or negatively. Family caregivers may have improved outcomes because they take care of themselves, or depression may lead them to neglect their health. The study demonstrates that risk assessments for caregivers need to be planned carefully and interventions need to be targeted in terms of the appropriate risk factors and outcomes.

As Zarit, *et al.* (2010) point out, this kind of multivariate analysis is not the norm, with most studies highlighting a specific stress pathway and focusing on one or two risk factors, 'targeting a mediator or moderator of the stress pathway so that its impact on an outcome can be mitigated' (p.220). This type of study can show clearer results than studies with multiple treatment components, but may assume that 'all caregivers experience the same risk factors...and as a result need the same treatment....a treatment that addresses a risk factor the caregiver does not possess, but fails to target ones that he/she does have is not likely to be effective' (p.221).

The rest of this section will look at research into various aspects of risk under general headings. This separation is not an easy task as risk factors can be hard to separate into discrete items, and researchers group or name the factors in different ways.

Psychological Aspects

Psychological resilience

Various studies refer to the transactional model of stress and coping when considering psychological factors, identifying that it is the family caregiver's appraisal of their situation that determines whether they experience stress or are able to develop coping strategies (e.g. Elvish, *et al.* 2012; O'Rourke, *et al.* 2010). O'Rourke, *et al.* (2010) use a similar process in their approach to the intrapsychic aspect of caregiver risk and examined three facets of psychological resilience (perceived control; commitment to living – i.e. the tendency to engage fully in daily activities; and challenge -a belief that life's challenges provide opportunities to increase one's skills and self-knowledge). These factors were considered as potential predictors of depressive symptoms in caregivers of persons with Alzheimer disease. Two aspects of resilience (perceived control and challenge) predicted lower levels of depressive symptoms, but commitment to living did not show predictive value. The authors suggest that this work could help to identify which caregivers are more at risk through being low in psychological resilience, to enable targeted early intervention.

UK based research on migrant and minority dementia caregivers have tended to focus on negative outcomes and less on their positive experiences. There is very little evidence that suggests what factors might protect the risk of poor outcomes in dementia caregiving for such communities. In addition to possible resiliency skills, religion and spirituality have been reported as important coping strategies for particular ethnic minority communities. Whilst many of these studies are US based, they inform our understanding of the factors that may protect migrant and minority dementia caregivers in the UK.

Jason (2010) researched psycho-social factors among Chinese American women caring for a family member with dementia. The results indicated that while these carers reported significant levels of distress, they also showed indications of resiliency, as suggested by their high levels of self-efficacy, positive caregiving experiences, and problem solving abilities. The salience of culture in shaping the caregiving experience was too highlighted – stronger beliefs in Asian values were associated with less depressive symptoms and greater self- efficacy. Clay, *et al.* (2008) also reported the resilience of African American caregivers, as displayed by their fewer depressive symptoms and higher levels of life satisfaction when compared to White dementia caregivers in America.

Religion, prayer and faith in God have been reported as instrumental in helping African-Americans to cope with caregiving (Haley *et al.* 2004; Jones-Cannon & Davis 2005; Farran, *et al.* 2003). Spirituality to help reduce the stressors of caregiving was a strong theme throughout these studies. Gerdner, *et al.* (2007) found that spirituality was an integral part of daily life for the majority of caregivers living in Arkansas Delta and was the deployed coping strategy for dealing with the challenges of caregiving. Such findings are reflective of the work of Jolley, *et al.* (2010) who researched people with dementia and their carers drawn from the population enrolled for treatment at a memory clinic in Wolverhampton in the UK. Their research demonstrated that spiritual beliefs are important for both the person with dementia and their carers in different ways

(Jolley, *et al*. 2010). Whilst this research predominantly involved the White British and Christian population, it demonstrates the importance of acknowledging religion and spirituality as a coping strategy to help protect the risk of poor outcomes for dementia caregivers. Tilki, *et al*. (2010) too reported religion to be an important aspect of the lives of older Irish people living in the UK.

Self-Efficacy

Research exploring self-efficacy have found that this is a partial protective factor in preventing depression (Alma, *et al*. 2010). Their study found that family caregivers who are high on scores of self-efficacy were more likely to be able to manage difficult/ negative thoughts; are at less risk of depression and report better physical health. This study and others appear to demonstrate that high levels of self-efficacy is positively related to the use of strategies such as problem solving in managing challenging situations, although it is also suggested that further research is needed to explore if supporting the development of self- efficacy would be a useful aspect of psychosocial interventions (Gallagher, *et al*. 2011a; Alma, *et al*. 2010; Gallagher, *et al*. 2011b).

Type of Dementia

The type of dementia experienced is also suggested to be a factor influencing psychological outcomes. Evidence suggests that the impact of the symptoms of other, less common forms of dementia such as Fronto-temporal dementia, Dementia with Lewy Bodies and Dementia associated with Parkinson's disease is significantly different, and is suggested to create higher levels of stress and distress in family members, resulting in earlier admission to care home settings. These difficulties arise from a variety of factors, including the specific symptom experience and the meaning that these changes have for family members. For example, one study highlighted that frontal variant fronto-temporal dementia had a significant impact upon the quality of the relationship between the person with dementia and their family member, resulting in the experience of loss of the relationship (Oyebode, *et al*. 2013). Furthermore, Lee, *et al*. (2012) found that increased stress in people with

Dementia with Lewy Bodies and Dementia with Parkinson's disease was associated with psychotic symptoms, daytime sleep, mood disturbance and fluctuations in cognitive impairment.

Professional response to request for services

Professional response to requests for help may also be a factor influencing psychological well-being. A small qualitative study (Robinson, *et al*. 2009) investigated how caregivers access information and services at an early stage; before and after diagnosis. They found that the difficulties experienced, including hurtful and dismissive responses, as well as the resolution of receipt of services created stress and emotional turmoil for some family members and delayed the receipt of services that were needed.

Communication styles

Communication style is also thought to be an important factor. Braun, *et al*. (2010) studied the role of marital communication in understanding caregiver distress and found that caregivers whose husbands used more positive communication reported less depression and distress. Where there was positive reciprocal communication this mitigated depression in caregivers, which showed the importance of interaction patterns to caregiver distress and depression. Again, this is a small scale study, however the findings are consistent with practice in such areas as family therapy, where communication is recognised to be an important facet of effective family functioning (Rolland, 1994; Walsh, 2006).

Meaning and motivations for caregiving

Quinn, *et al*. (2010) identified that finding meaning in providing care may be positively associated with the well-being of family caregivers. Their research following this initial systematic review identified that high levels of meaning were positively associated with high levels of competence; religiosity (high levels of observance of particular faith beliefs and practices); and high intrinsic motivations to care, including love and commitment. It was also associated with a low sense of role captivity

(Quinn, *et al*. 2012). These authors further suggest that the results lend strength to the belief that how caregivers appraise their role can have a positive effect on meaning.

Family caregiver characteristics

Schoenmakers, *et al*. (2010) carried out a systematic review of studies to identify those factors predicting the development of depression in family caregivers, as this outcome is consistent with placement of the person living with dementia in long term care. They found that although the experience of depression was associated with the level and intensity of the needs of the person with dementia, it was family caregiver characteristics that were most strongly associated with depression. These included; being female, a spouse caregiver and older. However, they also found that family caregivers who 'feel involved and supported in the care situation and look for solutions to problems in a reasonable way appear to cope best with the negative impact of a care situation' (p.199). Thus these authors concluded that further research considering the positive aspects of caregiving and the onset of depression is required.

Coping Styles

Li *et al*. (2012) completed a systematic review exploring whether changes in coping styles influenced psychological morbidity. They found that group interventions, while effective in improving depression, did not have an impact upon dysfunctional coping. They also found preliminary support for their hypothesis that interventions aimed at increasing emotional support and acceptance-based coping do influence improvements in psychological well- being, including depression and anxiety, although further research is needed. Furthermore, they found that studies focusing on solution-focused coping were not helpful in alleviating depression or anxiety. These authors concluded that further research is needed and that this particularly needs to include longitudinal studies. Other studies suggest that coping styles which involved wishful thinking, stoicism or avoidance were more likely to be associated with negative outcomes (Beinart, *et al*. 2012).

Physical Aspects

A number of recent studies have made strong links between caregiving for people living with dementia and a range of physical health problems.

Sleep and Physical Health Outcomes

McCurry, *et al*. (2009) reviewed literature on sleep problems for caregivers, and the enhanced risk of physical health problems associated with this. Poor sleep is linked to lowered immune function, elevated stress hormones, increased risk for cardiovascular disease, and risk for premature mortality. This data includes a 5 year longitudinal study of sleep problems in dementia caregivers and care recipients. They found that this area is generally under-researched, and most of the studies were small and based on self-report.

Cardiovascular disease and Stress

Aschbacher, *et al*. (2009) carried out a 3 year US study of the interaction between stress and depression linked to caregiving with cardiovascular disease (CVD) via chronic platelet activation. They found indications that persistent depression could increase risks of CVD in older caregivers. Similarly, Mausbach, *et al*. (2010) in another US study found a link between chronic stress of caregiving and impaired endothethial function, again linked to increased risk of CVD.

Autoimmune and metabolic disorders and Stress

A further study showed that exposure to multiple stressors was associated with elevated inflammatory markers in family caregivers, and that this is related to multiple recent stressful events experienced by family caregivers, not just the chronic nature of stress in caregiving (Gouin, *et al*. 2012). Holland, *et al*. (2011) also studied the impact of caregiving on the stress hormone, cortisol. They show evidence that disordered cortisol is associated with a range of health and mental health problems, including compromise of the immune system and higher risk of auto-immune-related and metabolic disorders. These authors found that family caregivers in

high intensity caregiving situations, with long hours of care and co-residence, had more disrupted cortisol patterns that are common in people who are chronically stressed.

Risk of developing dementia

In addition to these health risks, research has explored the increased risk for caregivers of developing dementia themselves. Vitaliano, *et al*. (2011) reviewed literature on relationships between caregiver status and risk of dementia in the context of a theoretical model of chronic stress. They found that the increased risk to caregivers of people with dementia in relation to non-caregivers may be a response to a range of different mediators. These include psychological factors such as depression, loneliness, social isolation and sleep problems, behavioural factors related to exercise and diet, and physiological factors related to metabolic syndrome and inflammation.

Relationship, Social Support and Familial Factors

Familism

Losada, *et al*.'s (2010) Spanish/US study aimed to examine cultural impact on the degree to which caregiving stressors affect caregiver outcomes. They refer to theories that culture may have a beneficial impact on well-being 'through its influence on the appraisal of stressors and the perception of social support' (p.193), using the concept of 'familism' as a basis for their study. They define 'familism' as 'a strong identification and attachment of individuals and their families (nuclear and extended), and strong feelings of loyalty, reciprocity, and solidarity among members of the same family' (p.194). They examined the influence on depression of both familism and dysfunctional thoughts specific to caregiving. 'Familism' was found to have both positive and negative influences. On the one hand, the family may provide a source of support; on the other hand there could be pressures to adhere to family values of obligation to provide support and family pressures regarding behaviour and attitudes that could affect emotional distress through

dysfunctional thoughts. They suggest that it may be useful to include both cultural and cognitive factors in assessment for interventions. They posit the problem that those caregivers with strong familism values as well as dysfunctional thoughts about caregiving may be difficult to reach although possibly the most in need, and argue there is a need for approaches that take into account the caregivers' varying profiles in order to tailor or adapt interventions to be more suitable for them.

Quality of the Relationship

Quinn, *et al*. (2009) completed a systematic review exploring the impact of the quality of the relationship on dementia caregiving. Similarly, Ablitt, *et al*. (2009) also considered the impact of relationship factors. Quinn, *et al*. indicated that some caregivers found dementia to impact upon relationship quality, and that both the previous and current relationship quality impacted upon carer wellbeing. Ablitt, *et al*. (2009) found that those family caregivers whose relationships were previously good tended to cope better with caregiving than those whose relationship was of poor quality. These family caregivers tended to experience higher levels of distress and burden. However both Ablitt, *et al*. (2009) and Fauth, *et al*. (2012) have cautioned against the assumption that positive relationships are always associated with better outcomes. They have found differences with some family caregivers with a previously positive relationship experiencing higher levels of distress. Indeed Fauth, *et al*. (2012) suggest that learning to detach from the relationship is associated with better caregiving outcomes, and is not necessarily associated with poorer care for the person with dementia. These authors further suggest that the quality of the previous relationship may have a direct influence on the way in which the family member now cares for the person. This is consistent with the work undertaken by Keady and Nolan (2003) who identify that the experience of dementia for the family caregiver and the person with dementia may result in different relational strategies, including working together, working separately, working alone or working apart.

Family Support

A number of authors have highlighted the importance of family and social support networks as mediating factors (Beinart, *et al.* 2012; Aggar, *et al.* 2010; Barnes, *et al.* 2013; Kwak, *et al.* 2012). Some intervention studies have found that directly addressing the availability and use of familial and social networks is positively associated with better coping and lowered levels of depression in spouse caregivers (e.g. Mittleman, *et al.* 2008; 2004). However the involvement of the wider family in interventions has not always been found to be effective, as the intervention described by Mittleman was implemented in the Netherlands, with no impact upon depression (Joling, *et al.* 2012).

Cultural Competence of Services and Understanding of Dementia among Migrant and Minority Communities

The factors that can increase the risk of poor outcomes for ethnic minority dementia caregivers have been well reported (Moriarty, *et al.* 2011; Jutlla, 2013; All Party Parliamentary Group, 2013). A number of UK based small scale research projects reported very similar findings about the challenges and issues for ethnic minority dementia caregivers (Moreland, 2001; Bowes & Wilkinson, 2003; Moreland, 2003; Seabrook & Milne, 2004; Jutlla & Moreland, 2007; Rochfort, 2008; Buffin, *et al.* 2009; Karim, *et al.* 2011; Tilki, *et al.* 2010; Jutlla, 2011).

There is a lack of dementia awareness among Asian communities in the UK, partly because there is no equivalent word for dementia in any of the South Asian languages (Seabrooke & Milne, 2004; Jutlla & Moreland, 2007). There is evidence also of a high degree of stigma in Asian communities attached to mental illness (Seabrooke & Milne, 2004; Jutlla & Moreland, 2007). Mental health issues are often evaluated negatively, leaving a cultural desire to portray an image of well-being to those outside the immediate family, as well as a need to hide the existence of mental health problems (Seabrooke & Milne, 2004; Jutlla, 2011).

These situations can, in turn, give rise to problems of detection due to isolation and a confusion of dementia with ageing giving rise to hidden carers unknown to services (Jutlla & Moreland, 2007). Due to such challenges, Asian people with dementia and their families often seek help from services when they are in crisis situations making effective intervention difficult (Saad, *et al.* 2008). Mackenzie (2006) in her study of South Asian and Eastern European family carers of a person with dementia living in the UK found that many of the family carers believed that a diagnosis of dementia was more likely to invite condemnation from others within their own cultures than in the majority white British culture. Thus leading to a tension around whether or not to engage with services and if so, how they are used. The need to address early diagnosis and intervention in Asian communities is thus becoming more prominent (Seabrooke & Milne, 2009; Moriarty, *et al.* 2011) and continues to be an identified priority in policy initiatives such as the National Dementia Strategy (Department of Health, 2009) and the recent All Party Parliamentary Group (2013) enquiry into the experiences of dementia in black, Asian and minority ethnic communities.

As research projects conducted to better inform policy and practice, they also noted the relative:

• Lack of detailed knowledge of dementia amongst GPs;

• Lack of knowledge and awareness of service provision and entitlements amongst carers, including voluntary organisations;

• Lack of cultural awareness, sensitivity and competence within health and social services, including language barriers; and

• Lack of understanding amongst carers regarding direct payments.

The literature also reports that Asians are generally reluctant to ask for support (Bowes & Sim, 2006; Rochfort, 2008). The pressures to conform to their

relational role to the cared-for person, and the lack of understanding about dementia and the caring role from the Sikh community have resulted in a reluctance to ask for formal support in the fear that they will become stigmatised by their community (Jutlla, 2011). Having a family member with dementia is also thought to jeopardise children's marriage prospects for those communities who practice arranged marriages and is thus another reason why such communities are reluctant to ask for, or accept, support for services in the fear that their circumstances will become public (Mackenzie, *et al.* 2003; Mackenzie, 2006).

There is thus a need to improve early detection of dementia, and tackle stigma, through the raising of awareness in migrant and minority communities and through in-service education for GPs and others working professionally with people with dementia and their families (Moriarty, *et al.* 2011; Jutlla, 2013; All Party Parliamentary Group, 2013; Jutlla, 2015).

Issues to be considered in Supporting LGBT people and carers

Given that LGBT people often have a range of relationships which may not follow typical heterosexual patterns, their relationships and their families may be more strongly based on "choice" rather than blood ties (Peel & McDaid, 2015). Therefore, maintaining links with LGBT networks is likely to be more important to LGBT people caring for someone living with dementia. Key support strategies may include support groups for lesbian and gay carers of people with dementia, a theme that recurs in the literature. For example, connecting lesbian and gay carers through a telephone support service or social media was raised in the "over the Rainbow" project as a strategy for providing a specific source of community and connection (Peel & McDaid, 2015).

Similarly, Price (2010) referred to the significance of LGBT groups as sources of support for LGBT people with dementia or LGBT carers as they provided a means of maintaining their LGBT identity and maintaining friendships and social networks. Supporting strategies

that enable this to happen is clearly important. It may also be important to address the risk that support in the future may not sustain the sexual identity and lifestyle choices of either an LGBT person with dementia or their LGBT carer.

Work focusing on identity and memory are recognised as key components of good person-centred care for people with dementia. Approaches that help LGBT people with dementia and /or their carers to feel safe in sharing their identity and life history will be crucial if they are to benefit from assessment, care/support planning and practice grounded in an appreciation of the person's life story or reminiscence therapy (Westwood, 2014).

Providing appropriate advice and support regarding services which meet the needs of LGBT people with dementia and/or carers who are LGBT people is essential but also complex. Providers may also need to consider alternative forms of housing and residential care provision for older lesbians and/or bisexual women with dementia who do not wish to live alongside men or for older gay men who do not wish to live with women or indeed heterosexual men.

Services and care practices that support LGBT people with dementia can themselves create LGBT-affirmative environments and increase professional caregivers' cultural competence. The limited evidence that is available concerning the provision of specialist services for LGBT people with dementia is inconclusive. In Price's (2010) study some respondents positively supported the concept of specialist provision with a shared culture and understanding of gay and lesbian sexualities, as a response to fears that services might not take into account their diverse identities. Others, however, were concerned that specialist provision might lead to the creation of ghettos.

Research has also highlighted particular issues or trans people with dementia, including complex social or bodily needs (Age UK 2015). For example, trans people living with dementia may also have medical issues relating to their natal gender that emerge with ageing, such as osteoporosis or prostate issues (Alzheimer's Society, 2013). Their cognitive difficulties may make this difficult

to understand. Dementia might cause someone who is a postoperative trans person to forget that external gender aspects have changed and, leading to confusion and distress. They may need reassurance and strategies to assist with personal care (for example shaving, hair or more intimate care) (Alzheimer's Society, 2013; Age UK, 2013). Trans people are also particularly vulnerable to discrimination in care settings, and their concern in this respect may result in avoidance of seeking support altogether (Birch, 2008). Anecdotal evidence of denial of services has been identified, as well as forcible prevention of cross dressing and intimidation when people are revealed to be trans within a care home setting (Birch, 2008).

Factors relating to the risk of abuse of the person with dementia

There are several studies that show the prevalence and risk factors of verbal, psychological and physical abuse by family caregivers of the person with dementia (Yan and Kwok, 2010; Pérez-Rojo, et al. 2009; Wiglesworth, et al. 2010; Cooper, et al.2010). Risk factors appeared to be related to:

- Co-residence, lack of domestic help, more observed agitated behaviour in the recipient of care, and higher reported caregiver stress (Yan and Kwok, 2010).

- The impact of caregiving, depression, and frequency of aggressive /provocative behaviours by the person with dementia and quantity of help received (Pérez-Rojo, et al. 2009).

- The caregiver's anxiety and depression, social contacts, perceived burden, and the care receiver's psychological and physical aggression.

- More anxious caregivers report more abusive behaviours, and that dysfunctional coping strategies and carer burden mediate this relationship and that abuse is related to the amount of hours spent caring and abusive behaviour from the care recipient (Cooper, et al. 2010).

- Negative and external motivations for caregiving, including for example other family members not being able to support the person were associated with reports of abusive behaviour after a year (Camden, et al. 2011).

These studies suggest that the number of caregivers reporting abuse is likely to be an underestimate, and that given the high prevalence rates of abusive behaviour found in family caregivers, assessment of these risk factors is important, as is further research to identify which interventions address these risk factors and support adaptive ways of coping (Cooper, et al. 2010; Yan and Kwok, 2010; Pérez-Rojo, et al. 2009; Wiglesworth, et al. 2010).

Who is at greater risk of poor outcomes?

While it is evident that there is considerable individual variability in the experience of caregiving, there is evidence that certain types of family caregivers are at greater risk of poor outcomes. This research is summarised below:

- Female caregivers are more often depressed than male caregivers (Schoenmakers, et al. 2010; Braun, et al. 2010).

- Spouses in general are more often depressed than other caregivers (Schoenmakers, et al. 2010).

- Glueckauf, et al.'s (2012) US study found that African American caregivers for people with dementia have fewer resources in terms of income and formal education than majority white caregivers. Despite the need for treatment of depression in this group, efforts to include them through outreach are limited by access issues of money and transport, as well as lack of cultural concordance of services and outcome research offered. However, given the different cultural context of this research, results cannot necessarily be applied wholesale to migrant and minority communities within the UK.

- Studies also highlight the significant challenges experienced by families in the context of a younger

onset of dementia. In their systematic review Svanberg, *et al.* (2011) indicate that there is considerable evidence of a significant impact upon family caregivers when a younger person experiences dementia, and that this impact may lead to a greater experience of negative outcomes than for caregivers of older family members with dementia. However further research is needed to establish the causal factors contributing to such outcomes.

• A systematic review of literature (Schoenmakers, *et al.* 2010) found that the level of dependence and deterioration in a person with dementia is related to caregiver depression, in particular where the person develops serious cognitive defects or disturbed behaviour. Results vary by relationship to the person with dementia and phase of the dementia, with partners more likely to be negatively affected by deterioration than other caregivers, and different phases of the dementia are found more stressful by some caregivers than others. However they indicate that further research is required to understand the relationship between negative feelings and the way in which the care situation develops over time.

• A few studies have addressed the combined impact of pre-existing disability and dementia. Family caregivers of people with visual and hearing impairments and dementia are suggested to require additional support, since people with impaired memory and visual impairment may experience greater levels of disorientation and distress. Some experience visual hallucinations which add to disorientation (Parker, *et al.* 2010; Lawrence, *et al.* 2009).

Assessment of factors influencing outcomes

Assessment is a fundamental aspect of delivering effective psycho-social interventions for family caregivers as an aid to targeting interventions appropriately. Zarit, *et al.* (2010) suggests that assessments for caregivers need to be planned carefully and interventions need to be targeted in terms of the appropriate risk factors and outcomes. Consistent with other reviews, they

further indicate that as caregivers represent a heterogeneous group with significant individual variability in the experience of risk factors, assessment is a complex process. Many of the psycho-social interventions developed in research have used a number of assessment measures; however this represents a considerable challenge when translating such processes into practice, where such issues as time factors may limit the ability to use a range of measures (Zarit, 2006). Zarit, *et al.* (2010) therefore identify that assessment of family caregivers needs to be multidimensional, and that no one measure can realistically capture all of the risks and possible outcomes for any family caregiver. Thus the Family Caregiver Alliance (2006) identify a range of areas that should be addressed in a systematic assessment of family caregivers, as follows:

• Context of care.

• Family caregiver perception of the health and functional status of the person with dementia.

• Family caregiver values and preferences.

• Family caregiver well-being.

• Consequences of caregiving.

• Skills/abilities/knowledge to provide care.

• Potential resources.

Thus while measures can be used, it is also important to gain an understanding of the individual and relational factors, needs and experiences of the family caregiver in order to inform care planning and intervention.

Examples of assessment processes which might be of value include Stirling, *et al.* (2010). These authors highlight the limitations of current assessment processes and suggest that the complexity of family caregivers' needs make it difficult to rely on measures of carer burden and care-recipient dependency for

assessment. They carried out a study in Tasmania with 20 family caregivers who completed self-report measures on carer burden and stress, completed a diary of service usage, and participated in semi-structured interviews. They concluded that family caregivers can recognise when they would like more help from services, even if standard measures of carer burden do not clearly indicate unmet service needs. They advocate asking family caregivers a question designed to elicit their felt need, as a way to recognise growing caregiver stress. They suggest that assessment of service needs '*should recognise the fallibility of carer burden measures, given that carer stress may not only come from caring for someone with dementia, but can be significantly compounded by other life situations*' (p.1).

Carers' Needs Assessment for Dementia (CNA-D) Schölzel-Dorenbos, *et al*. (2010)

As with Stirling, *et al*. (2010) these authors also addressed 'real life' perspectives on needs assessment for family caregivers and persons with dementia, stating that 'reliance solely on assessment of needs by professional caregivers may lead to under recognition of personal unmet needs'. They reviewed literature on the measurement of needs and health-related quality of life (HRQol) in relation to dementia, basing their approach on Maslow's Hierarchy of needs in order to design a dementia-specific model. They reviewed literature on measures of needs, determining that the Carers' Needs Assessment for Dementia (CNA-D) is a valid instrument to assess needs of caregivers. They argue that people with dementia and family caregivers would be likely to benefit from an intervention system guided by unmet needs and HRQoL assessment, carried out by a case manager.

Finally, Yarry, *et al*. (2010) described a recently designed intervention called ANSWERS, that works with both members of a caregiving dyad, using a strengths-based inventory to assess the current strengths and abilities of each care partner in relation to cognitive and physical health, and areas of social and leisure activity, personality, history and culture. They present

two case examples and discuss how this method enabled deeper assessment of each dyad's strengths and care needs, so that intervention could be tailored to suit both care partners and include them as active participants in the process.

Interventions to support family caregiving and reduce the risk of poor outcomes

This section explores the psycho-social interventions that have been developed to support family caregivers, improve psychological, physical and social well-being nd ultimately, reduce the risk of poor outcomes. This is achieved by firstly reviewing recent systematic reviews, meta-analyses, and reviews to provide an overview of the common factors promoting success in interventions. Within this section, the studies that have achieved prominence because they have achieved demonstrable long term outcomes or translation into clinical practice are described.

Following this summary, recent literature which provides evidence of psycho-educational, multicomponent, psychological, peer support, will be described, alongside evidence of innovative methods of translation into practice, including technological and new media applications. Finally, the gaps in research concerning psychosocial interventions are summarised.

Summary of recent systematic reviews, meta-analysis and reviews of the literature

As indicated earlier, there is considerable interest in the identification of interventions that can support people living with dementia and their families, in order to address their well-being needs and maintain people at home (Gallagher-Thompson, *et al*. 2012) Therefore, a large number of psychosocial interventions have been designed over many years in order to address the factors that influence negative outcomes in caregiving. Given the significant number of interventions available in the literature, a number of systematic reviews, meta- analyses and reviews have been completed in recent years, and

have identified the interventions and the characteristics of those interventions that have demonstrated the most success. These factors are now discussed (Gallagher-Thompson, *et al.* 2012; Elvish, *et al.* 2012; Nunneman, *et al.* 2012; deVries, *et al.* 2010; Selwood, *et al.* 2007).

These reviews demonstrate that the most successful interventions are those which recognise that family caregivers have heterogeneous profiles of risk factors thus there is a need to tailor treatments to individuals, since one size does not fit all (Elvish, *et al.* 2012; deVries, *et al.* 2010). Beinart, *et al.* (2012) when reviewing psycho-educational interventions, have also highlighted that interventions that are individually tailored to the needs of the family are particularly effective and require further investigation. Gallagher-Thompson, *et al.* (2012) also summarise the evidence in the field and in addition to the need for tailored interventions, suggest that the most successful interventions are those which involve the person with dementia as well as family caregivers. The involvement of the person with dementia as well as family caregivers provides opportunities for the development of a shared construction of their situation, a factor which may assist in addressing the impact of dementia upon the relationship (Elvish, *et al.* 2012; Moon and Betts Adams, 2012).

In terms of what is provided, Gallagher-Thompson, *et al.* (2012) suggest that there is no universally effective intervention to improve the quality of life of family caregivers and further evidence is required to consider who benefits most from particular interventions and at what stage. Evidence for effectiveness of specific interventions tends to focus upon 4 main areas; Psycho-educational, Multi-component, Psychological interventions and most recently, technological interventions.

Psycho-educational Interventions

It is suggested that while it is possible to improve family caregiver's knowledge of dementia, this knowledge development appears unrelated to psychological and social outcomes (Selwood, *et al.* 2007). In order for educational interventions to be effective, they are required to contain additional psychological and social elements (Selwood, *et al.* 2007; deVries, *et al.* 2010). Psycho-educational interventions tend to include psychosocial training together with an educational component; covering information about the disease; the organisation of care; practical advice for coping; skills training to manage the behavioural changes associated with dementia; decision making skills; advice about the emotional experience of caregiving and self care (Beinart, *et al.* 2012; Gallagher-Thompson, *et al.* 2012). Generally, such interventions are delivered over a specific time period, such as 12 weeks and are generally delivered in small group settings by specially trained individuals.

Evidence for efficacy of psycho-educational interventions demonstrates that they address caregiver well-being, including depression and stress, attitudes towards caregiving and anxiety, although no evidence exists as yet for delays in admission to care home (Gallagher-Thompson, *et al.* 2012; Elvish, *et al.* 2012). Furthermore, these effects were demonstrated to be maintained over time. In order for such interventions to be successful, it has been identified that family members need to actively participate in decisions about the content of the intervention, the delivery and the development of skills associated with the sessions and that the information needs to be tailored to the specific problems they experience (Spijker, *et al.* 2008; Selwood, *et al.* 2007; deVries, *et al.* 2010). Furthermore, it is suggested that the provision of on-going, interventions, including specific information about services, coaching regarding their role, and targetting the person living with dementia particularly through reduction in behaviours as the journey of dementia progresses are additional elements of successful interventions (deVries, *et al.* 2010; Elvish, *et al.* 2012). Elvish, *et al.* (2012) also indicated the importance of the social element contained within such interventions, identifying that this fulfilled an important role in enabling family caregivers to build their networks of support. Finally, Elvish, *et al.* (2012) identify that many of these interventions are guided by two main theoretical frameworks, the Transactional Model of Stress and Coping or Cognitive Behavioural Principles, however it is evident that other psychological models have not necessarily been applied in this field.

Multicomponent Interventions

Reviews have indicated that multi-component interventions which address psychological and social components appear to be the most effective in improving wellbeing and are also identified as being effective in delaying admission to long term care (Gallagher-Thompson, *et al.* 2012; Elvish, *et al.* 2012; Smits, *et al.* 2007). Multicomponent interventions typically include individual and group sessions; often involve the person living with dementia in some aspects of the programme and provide a range of different strategies including; information; role playing; problem solving; skills training; stress management; self-care; psychological and social interventions, including family therapy (Elvish, *et al.* 2012; Gallagher-Thompson, *et al.* 2012; Gallagher-Thompson & Coon, 2007; Spijker, *et al.* 2008; Smits, *et al.* 2007).

Evidence for effectiveness suggests that multicomponent interventions that combine individual and group sessions appear to be most beneficial. Furthermore, the length and intensity of the interventions were viewed to be particularly important with efficacy being greater in six or more sessions of multi-component interventions, which are intensive and followed by the delivery of on-going support (deVries, *et al.* 2010). As with psycho-educational interventions, Elvish, *et al.* (2012) highlight the importance of the social component of the intervention being a significant factor in enabling the family caregiver to develop their familial and social networks.

Psychological Interventions

Psychological interventions encompass a range of interventions including counselling, psychotherapy, family therapy as well as psychological interventions provided as an aspect of the other interventions described above (Elvish, *et al.*2012). These interventions are frequently used to address outcomes such as depression, burden, well-being and social support; although Elvish, *et al.* indicated that some studies have been more specific in the specific aspects they are targeting, including self-efficacy and distress in

dealing with agitation. The most common interventions described are based upon Cognitive Behavioural Therapy, and include behavioural management interventions (Gallagher-Thompson, *et al.* 2012; Selwood, *et al.* 2007). These authors indicate that interventions underpinned by cognitive/cognitive-behavioural models produce meaningful change. However, Elvish, *et al.* (2012) indicate that studies utilising other models of counselling and psychotherapy are not in evidence in research, therefore it is difficult to draw conclusions about whether other counselling approaches may be helpful.

Gallagher-Thompson, *et al.* (2012) discusses early results from an intervention based upon acceptance and commitment therapy, which is derived from cognitive behavioural interventions. As indicated earlier in this review, emotional and acceptance based coping styles are viewed to be important factors influencing coping and lower risk of depression and anxiety (Li, *et al.* 2012). Therefore Gallagher-Thompson, *et al.* (2012) suggest that supporting the development of these coping styles in psychological interventions is promising and will assist family caregivers to become more aware of the values underpinning their motivations and driving their actions in caregiving.

Technological Interventions

Various reviews have identified that this is a promising area of development in interventions for family caregivers and is also a rapidly expanding area as new technologies develop (Gallagher-Thompson, *et al.* 2012; Elvish, *et al.* 2012). Technological based interventions are commonly consisting of the interventions described previously, but delivered using new media formats, including teleconferencing, videophones, skype, telehealth, internet based, online support groups, DVD products and finally assistive technologies. Such interventions are particularly important given the challenges associated with delivering interventions in the changing economic, social and environmental contexts within which we live. Furthermore, they can make interventions available to those who might not be able or willing to access traditional support for families involved in caregiving, such as those living in rural areas, who have familial or work

responsibilities and people from migrant or minority communities (Gallagher-Thompson, *et al*. 2012; Elvish, *et al*. 2012).

Elvish, *et al*. (2012) identify that the evidence of effectiveness is strong within their review, with all of the 5 studies finding significant results on outcomes including depression, burden and social support, as well as demonstrating improvements in well-being. For example, Marziali & Garcia (2011) found that a video based intervention was equally as successful as face to face groups in improving mental health status and lowering stress.

Studies contributing to long term impact on outcomes and/ or translation into practice

As previously indicated, a large number of intervention studies for family caregivers have been designed and implemented over many years, and a significant proportion of these have been evaluated in numerous systematic reviews and meta-analyses. However, it is recognised that many studies have only been evaluated for short periods of time, thus longer term outcomes are frequently not know, furthermore the translation of research studies into practice settings remains challenging (Zarit, *et al*. 2010; Zarit & Femia, 2008; Stevens, *et al*. 2009; Mittleman, *et al*. 2004b). Some authors have attempted to address these issues by assessing longer term outcomes and through translation studies including; the New York University Intervention and REACH I and II as described below.

New York University Intervention (Mittleman, *et al*. 2004a, 2004b, 2008)

The New York University Intervention began in 1987, and was designed to address the experience of depression in spouse family caregivers of people living with dementia. Interventions began by enrolling 406 spouse caregivers in two successive cohorts of interventions, with family caregivers being randomly assigned to an enhanced counselling and support intervention, or to usual care. The intervention was designed to 'improve caregiving skills, mobilize the support of naturally existing family

networks, and provide the opportunity for counselling as needed over the entire course of caregiving' (p.850). The project followed family caregivers for 9.5 years, with the results demonstrating that the intervention was effective in reducing symptoms of depression when followed up after one year. Furthermore, the results indicated that family caregivers in the intervention group had significantly lower depression scores than the control group up to 3.1 years after commencement in the study. These results were shown to be consistent across gender and dementia severity, and shown to be maintained even after the person with dementia was admitted to institutional care. The authors suggest that the success of the intervention lies in its flexibility, as family caregivers were able to access support as their needs changed and new or altered coping strategies and skills were required. A further study across three countries (United States, United Kingdom and Australia) replicated the NYU intervention and combined it with the prescription of Aricept for persons with dementia (Mittleman, *et al*. 2008). Five sessions of individual and family counselling within 3 months of commencement on the study were offered, followed by ad hoc counselling, mostly provided by telephone, were delivered, for half of the study participants. All of the persons with dementia were prescribed Aricept. The intervention involved one individual session, followed by three sessions in which the family of the caregiver were invited by them to attend, followed by one final individual session.

Predominantly in the study, the follow up was then provided as telephone counselling sessions as they required it, for the duration of the study.

The content of the sessions depended upon the detailed assessment of the family caregiver's needs and wishes, and included as required, information, education, resources and managing difficult behaviour. However an underpinning theme was the emotional support and assistance provided to the family caregiver. Again, this study demonstrated significance in reduction of depression scores across all three countries and that this reduction continued over the 2 years of the study. Furthermore that the difference in depression rates between those receiving the intervention and those that

didn't widened over the two years. The authors conclude by indicating that although there are limitations to their study and that further studies are required, their approach provides benefits family caregivers and 'that a fairly modest intervention by skilled personnel can pay handsome dividends which continue over at least two years' (p.8).

REACH I and II (Schulz, *et al*. 2003; Belle, *et al*. 2006)

These studies were designed to develop and test effective interventions for caregivers in the USA, with the aims of decreasing burden and depression. Interventions were tested at six US sites in the first phase, finding that interventions had superior outcomes to controls, but that interventions with active engagement in skills training were the most effective. REACH II interventions were therefore designed to target problem areas in ways tailored to individual needs, and actively engaging caregivers in the process. The interventions were delivered in five US cities to 212 Hispanic or Latino, 219 white or Caucasian, and 211 black or African-American caregivers. Caregivers determined the specific interventions they would receive. A six month assessment found that quality of life improved for the caregivers who received the intervention, in comparison to controls, though did not affect how many care recipients were institutionalised. The study has been influential and other researchers have carried out studies related to REACH.

Subsequently, Nichols, *et al*. (2011) implemented a study of the first national clinical translation of REACH II. Interventions were individualised using risk assessment, and the skilled interventionist taught problem solving skills and action-oriented strategies to target problems with caregiving or behaviours of the person with dementia. Interventions included stress management techniques relating to physical wellness and mood management for the caregiver. At the start of the programme, many of the caregivers reported feelings of being overwhelmed, tearful, frustrated and lonely, and in worsening health. Outcomes at six month follow up showed significant improvements in burden, depression and its impact on their lives, and frustrations of caregiving. There were significant reductions in

behaviour problems of the person with dementia, and a reduction of almost 2 hours a day in time spent caregiving. The authors argue that these findings have clinical significance in lessening the potential for abuse in a group which had typical risk factors for abuse. Some caregivers said the interventions helped them learn to manage troubling behaviours and stress before a crisis occurs.

Stevens, *et al*. (2009) also carried out an implementation research programme aiming to implement REACH work. They argued that although the REACH II interventions were effective, they required a large number of face to face contacts with skilled, well-trained professionals, which is unrealistic to implement in routine practice. They developed a model of community-based implementation with volunteers using an established model named 'Support Team Network', founded on 'a team-based approach with 4 basic guiding principles: do what you can, when you can, in a coordinated way, and with a built-in support team' (p.S85). Seven support teams were recruited to support seven caregivers and further teams are being recruited. The authors believe this to be an effective translation into clinical practice although longer term outcomes are not addressed.

Another programme based on REACH was carried out by Au, *et al*. (2010) in Hong Kong. They adopted a Coping with Caring intervention which was developed as part of the REACH programme specifically for Chinese Americans. This achieved good results in improving caregivers' self-efficacy and coping flexibility. The intervention was based on Cognitive Behavioural Therapy which the authors considered to work for Chinese clients as their culture emphasises practical problem solving.

Recent psycho-social interventions

Taking into account the evidence presented above, this next section will describe various recent interventions that have some evidence of efficacy and where possible, UK studies will be included. These descriptions seek to highlight particular issues that are faced in delivering such interventions where possible, although information concerning what is delivered is frequently limited in published research. However, it should be noted that

although this research is positive in identifying ways forward in supporting family caregivers, there are a number of acknowledged limitations which are effectively summarised in recent reviews. These include that:

- There is a mismatch between 'real world' outcomes that achieve a reduction in symptoms or improvement in wellbeing in family caregivers and the outcomes measured in research studies, which are frequently about achieving research significance (Zarit & Femia, 2008).

- Intervention studies do not always target those who actually need the intervention being delivered thus the effectiveness of interventions is not always evident (Zarit & Femia, 2008).

- It is suggested that definitions of caregiving vary between studies, with many setting low thresholds in order to simplify recruitment processes. This further complicates assessment of what works and what doesn't work and for whom it works (Schoenmakers, *et al.* 2010).

- Family members involved in caregiving are not a homogenous group, thus designing interventions that meet a wide range of needs is complex (Zarit & Femia, 2008).

- Studies are largely carried out in the USA and are therefore not necessarily directly transferrable to the UK, this is particularly true for those studies addressing migrant or indigenous minority communities (Elvish, *et al.* 2012).

Consequently it will be necessary to assess the transferability of such interventions to practice in the UK with these limitations in mind.

Psycho-educational Interventions

Carer Information and Support Programme (CrISP) Barnes, *et al.* (2013), Alzheimer's Society

This study evaluated an intervention designed and delivered by the Alzheimer's Society in 19 localities in England and Wales. The programme was delivered on 26 occasions and comprised of two parts;

- Part One: for carers and family members of a person with a recent diagnosis comprising 4 sessions covering understanding dementia, legal and money matters, providing care and support and finally coping day to day. This was rolled out over 19 localities in England and Wales, and was delivered in 4 sessions in the majority of areas

- Part Two: For those who have been living with dementia for some time, comprising 3 sessions which explored how dementia progresses and the changes associated with seeking to live with dementia through such progression

The programme had the following aims and outcomes (p.1);

Aims

- Provide and improve access to good quality information.

- Empower carers to access support services and financial benefits and entitlements.

- Enable carers to plan for the future.

- Help carers to feel better informed and less isolated.

- Help carers to feel that they cope better within their caring role.

Expected Outcomes

- Carers are provided with access to a forum.

- Carers are provided with information in an understandable format.

- Carers feel that they have increased knowledge of dementia.

- Where required, carers feel they have been supported to access help and services from the Society and others.

- Carers feel they have been provided with practical information that they can use in coping with living with dementia day-to-day.

- Carers feel that they have received information and an understanding of how to plan with and for the person they care for now and in the future.

- Carers feel they have benefitted from peer support and sharing experiences.

A qualitative evaluation of the intervention was undertaken, which highlighted results that could be helpful when designing and delivering such interventions. Some of these include:

1 The authors found that the courses need to take into account the considerable diversity in caregiving experiences, influenced by many of the factors previously mentioned in this review, including the difference between family caregiving relationships, ethnicity, and gender, thus affirming studies that indicate that a 'one size fits all approach' is not helpful (Elvish, *et al*. 2012).

2 Participants varied in terms of how beneficial the course was for them, while the majority found it to be beneficial, a proportion did not. Thus it would seem that this reinforces the need for individual assessment to determine what family caregivers need and want before offering an intervention.

3 Carers were often at different points in their journey with dementia and were not necessarily comfortable with being in mixed groups with people who were further down their journey with dementia. Furthermore, some did not necessarily want information about the future and the likely progression of dementia, being in a mixed group may well have made it difficult to be responsive to these different needs.

4 Many of the carers would have valued opportunities to sustain the contacts with other carers following the end of the course, but this wasn't available to them.

5 Some participants found the volume of written information to be overwhelming, and would have preferred it to have been presented in an indexed folder to allow ease of access and selection of information appropriate to their needs. Furthermore, participants found that information which was delivered and made relevant to their situation was more helpful, as was visual information.

6 The need for opportunities to revisit information gained in the initial course was identified as important by participants, as well as to make contact with other carers.

The above summarises some of the outcomes from this qualitative study. Further details can be found at; www.brighton.ac.uk/sass/research/publications/CrISP-Report.pdf. It is important to note that whilst this is a qualitative study and therefore limited in transferability, many of these outcomes are common to the concerns raised within other research concerning what families and people living with dementia need and want.

An evaluation of a 'Course for Carers' providing psycho-educational support for relatives of people with a recent diagnosis of mild to moderate dementia, Milne, *et al*. (2014)

This study provided a systematic evaluation of a rolling programme of seven courses each with a 10 two hour sessions of a multi-component psychoeducational intervention for relatives of people with a recent diagnosis of mild to moderate dementia(an MMSE score of 15 or above). 113 participants took part in the courses and evaluation tools included a quantitative rating scale and qualitative data.

The course formed part of the post-diagnostic pathway alongside a parallel support group for the person with dementia. Experience of delivering generic carers courses had demonstrated that the needs of carers of people with mild dementia were different to those at later stages and also that carers at the same stage became a more cohesive group.

Full Report

The aims of each course were to:

1 Assist in overcoming the shock and grief associated with diagnosis of dementia,

2 coming to terms, and preparing for the dementia journey,

3 Support relationships and communication with the person with dementia,

4 Provide a focus on maintaining function, optimising health, quality of life and wellbeing,

5 making best use of existing skills and time,

6 Increase knowledge and understanding of dementia, causes, progression and effect on behaviour and personality,

7 Provide factual knowledge e.g. about legal issues and drug treatments,

8 Raise awareness of the stresses of caring for a person with dementia and provide strategies to recognise and manage stress e.g. relaxation techniques, cognitive behaviour and emotion focused coping,

9 Equip carers with understanding of local support services and how to access, building competence and confidence in contacting and dealing with local services at appropriate times.

The evaluation suggested that the courses for carers were highly valued by them and that a structured course after diagnosis Is effective in terms of: providing emotional and psychological support; offering practical help and advice; enhancing coping skills; supporting the relationship and communication between the carer and their relative; boosting confidence; increasing knowledge about dementia, symptoms, treatments and services; and preparing the carer for the future. These courses were epitomised by their focus on providing a safe place for participants to speak openly about fears and difficulties. The evaluation suggested that the course has short term

preventive potential and probably longer term benefits; also that it could be a model which could be replicated.

A service evaluation of a programme for carers aimed at helping occupational performance through engagement, Hampson & Smith (2015)

The Helping Occupational Performance through Engagement (HOPE) programme consists of a series of seven workshops, delivered by a qualified occupational therapist and a technical instructor, which aim to equip family carers to engage their person with dementia in meaningful daily occupation, maintaining their skills, wellbeing and personhood. The workshops are themed around: activities of daily living; roles, routines and habits; reminiscence; life story work; the environment and sensory stimulation.

This evaluation was completed on the initial two programmes. It incorporated questionnaire and focus group data obtained from ten participants across the two programmes. The evaluation identified that participants felt enabled to maintain skills of the person with dementia and support them in daily occupation; also carers were more confident and aware of the impact that they had on the person with dementia and what engaged them.

This was a small scale study which appeared to show that the programme fulfilled its aims, however some amendments were indicated and further evaluation is required to establish the long-term impact of the programme.

A systematic review of general practice based psychosocial interventions for supporting carers of people with dementia, Greenwood, et al. (2016)

Four (three from the US and one from Spain) studies were identified, involving 447 carers. There is clearly a limited evidence base to draw upon.

The interventions aimed to use information and educational materials to improve carer mental health, dementia knowledge, caregiving competence, reduce

burden, difficulties and frustrations. The detail of the interventions was limited; but whilst they appeared primarily to provide information, some interventions also appeared to address personal needs by providing support, skill training, and problem-solving.

Overall the evidence suggested that these interventions may improve carer well-being and emotional health by improving their ability to cope with the symptoms of dementia but the impact on physical health, quality of life and feelings of burden were not statistically significant. Furthermore the impact on depression, understanding of dementia and caregiving competence, was contradictory across the four studies.

The authors of the review suggested that the findings across the studies should be viewed with caution as the diversity of the outcomes and measurement tools used made cross-study comparison difficult.

The available evidence suggested that general practice could have a role in the support of carers but further research is required.

Psycho-educational Interventions for family members from migrant or minority communities

A number of initiatives have sought to address poor dementia awareness levels in ethnic minorities through information and education interventions. However, these interventions have little been reported nor evaluated. Nonetheless, based on the factors that increase the risk of poor outcomes for such communities, information and education programmes are key interventions to support family carers from migrant and minority communities. While based in Australia, Boughtwood, *et al.* (2012) provide novel insights to the information needs of dementia carers from culturally and linguistically diverse communities and report that the interpersonal aspects of information dissemination are important for such communities. These authors found that how well the information is received, understood and evaluated is strongly affected by the characteristics of the person passing on the information. Such characteristics included their knowledge, professionalism, trustworthiness, care

and connections with the community. Also highlighted in their study is the use of mass media (radio and television due to people's problems with literacy) and information campaigns. The authors emphasise that such information delivery should be innovative and reflect the circumstances and the needs of the communities in question.

They recommend that stakeholders from within these communities are involved in all stages of the development and dissemination of dementia information resources. Through the volunteer-led health and social care programme, the Alzheimer's Society has developed a pilot project for 'Connecting Communities in London.' Taking into consideration the current challenges, this project aims to improve dementia awareness through information and support for people living with dementia from minority ethnic communities in eight London boroughs (see: www.ehospice.com/uk/Default/tabid/3259/ArticleId/1696#.UOREUuQ9qSo).

Targeting problem behaviours of the person with dementia, Gitlin, *et al.* (2010)

A US based randomised trial by with 272 family caregivers and people with dementia aimed to reduce the frequency of problem behaviours and improve caregivers' ability and confidence to manage them. This intervention included educating the family caregivers about the causes of problem behaviours, including detection of undiagnosed medical conditions, communication and environmental factors. There was a significant improvement at 16 and 24 weeks for the intervention group's confidence, with reduced upset and depression, compared to controls, and 34% of the people with dementia were found to have undiagnosed health problems that were followed up.

Interventions assisting with grief following care home admission, Paun and Farren (2011)

These authors refer to research that caregivers do not relinquish their role after placing a family member with dementia in long-term care, and report increased emotional upset around the time of placement, with

sustained losses over time leading to chronic grief, which increases their risk for depression and suicide. They developed a Chronic Grief Management Intervention (CGMI) designed to help caregivers cope with grief at this stage, building on existing evidence of what works. They pilot tested the 12-week intervention with 34 caregivers in the US. The intervention had three major components: '*(a) knowledge; (b) communication, conflict resolution, and hands-on care skills; and (c) chronic grief management skills and processing loss*' (p.31). Groups were held with skilled facilitators over twelve weeks. Evaluations of the programme at 3 and 6 months showed that the participants found the intervention helpful and would have liked it to go on longer than 12 weeks. Some made occasional suggestions for improvement to group co-leaders.

Nunneman, *et al*. (2012) considered the efficacy of psycho-educational support groups for families living with a person with fronto-temporal lobar dementia (FTLD). They identified that literature concerning interventions for families living with this form of dementia are uncommon, and there are no randomized controlled trials. They reviewed four papers detailing support groups for family caregivers of people with FTLD:

• Diehl, *et al*. (2003), 7 weekly 90 minute sessions with 8 caregivers, topics comprised educational and therapeutic elements. Evaluation occurred immediately after and at 6 months post intervention. Benefits included the opportunity to share problems, learn from each other, shared coping strategies, and new social relationships. Only three people evaluated their own needs more positively as a result of the intervention, even though this was a goal of the intervention. Continued support is offered through a monthly support group.

• Reah, *et al*. (2008), quarterly to bi-monthly meetings with talks, management of behaviour symptoms, access to support services and discussion of personally relevant issues. After 2 years of attendance, a postal questionnaire demonstrated improved skills in all topics, better communication and emotional coping.

• Banks, *et al*. (2006) provided three conferences over one year that sought to educate and support caregivers. These were for a half day, involving time for lectures and questions. A 90 minute support group session was then delivered during which time was also allowed for discussion and sharing of experiences, share strategies and practical tips. Participants evaluated the sessions positively, but wanted more frequent sessions and time to develop knowledge on such issues as driving and taking over responsibilities.

• Marziali & Climans, (2009) provided weekly meetings over 10 weeks, provided by video-conferencing. These were facilitated by a healthcare professional. The provision of this facility through the internet was well received due to the time commitments of family caregivers including work and managing household and children's needs. The evaluation identified that the biggest gain was in knowing they were not alone. The emotional support assisted them to feel less burdened but did not affect stress levels.

Nunneman, *et al*. (2012) reviewed other forms of support and suggested that it is possible that caregivers would prefer combined, multicomponent interventions which include support groups and day care for the person with FTLD over support alone. They identified that it was essential that interventions addressed management of behavioural problems; coping strategies; environmental modification and psychological interventions given the high level of stress experienced by family caregivers of people with FTLD. They also concluded that technological methods of providing support would be particularly useful given the small number of families affected by FTLD and the difficulties associated with the competing demands of work, family life and household management frequently facing such families.

Multi-component interventions

The Meeting Centres Support Program, Droes, *et al*. (2006)

The meeting centres support program is a comprehensive support programme which was

developed in The Netherlands in the early 1990's. It is informed by the adaptation-coping model and brings together different forms of support that have been found to be effective in research including;

• 8 to 10 Informative meetings;

• Twice weekly long term discussion group for carers;

• Social activities for carers;

• Social club for the person with dementia 3 days per week (including recreational activities, reality orientation and reminiscence);

• Case Management; and

• A weekly consulting hour which can be utilised by both family caregivers and people with dementia.

This programme has the goal of improving knowledge, sense of competence, as well as providing social and emotional support. The authors indicated that the person with dementia and their family caregiver are supported to cope with the tasks that they encounter because of dementia, including coping with disabilities, emotions, and self-image. This study sought to determine if the results from an initial evaluation were replicated in a larger, multicentre implementation of the program. A control group was identified who received usual day care provision. Psychological and physical well-being were assessed as well as carer burden and satisfaction. Sense of competence, coping strategies, family support, loneliness and the emotional impact of behaviour problems were also assessed.
Data collection occurred over 29 months.
The interventions resulted in a decrease in burden and delays in placement to nursing home. The effect on psychological and psychosomatic symptoms was considered small. Furthermore, while the range of behavioural problems by the person with dementia increased, the emotional impact of these behaviours on family caregivers remained stable.

Multimodal intervention including Tai Chi, CBT and Support Group, Burgener, *et al.* (2011)

Burgener, *et al.* (2011) carried out a study of a multimodal intervention with a delayed intervention control group with 24 persons with dementia and family caregivers at an early stage of the dementia. The intervention for the people with dementia was Tai Chi exercises, CBT and cognitive training exercises, and support group participation. Caregivers had the option of participating in the Tai Chi and the support group only. Control group caregivers participated in educational programmes and were given the intervention later. Caregivers were assessed for role stress and the quality of their relationship with the person with dementia. The intervention group showed no significant difference between those choosing to participate and those not, but there was a difference between intervention and control groups in terms of a more positive quality of relationship with the person with dementia in the intervention group. A number of the non-participating caregivers commented on the positive effects of the intervention on the person with dementia, and the authors point to the clinical significance of the improved quality of relationship for caregivers, as the control group caregivers increased their scores for negative relationship during the trial.

Reducing need for institutionalisation, Eloniemi-Sulkava, *et al.* (2009)

A randomised controlled trial in Finland sought to establish whether a two year multi- component intervention programme for caregivers and people with dementia would prevent institutionalisation. The participants were 125 couples, with 63 being allocated to the intervention group and 62 to the control group. Couples receiving the intervention had a family care coordinator; goal oriented support groups; investigations by a geriatrician, and individualized services, some developed with the family caregivers. Institutionalisation was shown to be delayed in the intervention group as at 1.6 years twice as many people with dementia in the control group were in long term institutional care as in the intervention group, but at two years there was no

significant difference. However the programme did show that the intervention group used significantly less community services than controls.

A multi-component dyadic intervention on the psychological distress of family caregivers providing care to people with dementia, Prick, *et al.* (2015)

The intervention, conducted in the Netherlands, aimed to reduce psychological distress of people with dementia and carers. It was adapted from a trial in the US (Teri, *et al.* 2003) which had demonstrated positive outcomes for people with dementia. The physical element of the adapted intervention (incorporating flexibility, strengthening, balance, and endurance exercises) aimed to motivate people with dementia and carers who were not physically active to complete 30 minutes of active exercise at least 3 days a week, or to encourage dyads who were already active to maintain a minimum of 30 minutes active exercise 3 days a week and preferably increase to most days of the week. The support component incorporated three elements: (a) psycho-education, (b) communication skills training and (c) enjoyable activities training.

This study focused on 111 dyads and considered outcomes for the person with dementia and their carers. The experimental group received eight home visits over a three month period, combining physical exercise and support focused on both the person with dementia and their carer. The comparison group received monthly information bulletins and phone calls. There were three measurements at baseline (prior to the intervention), at three months, and at six months from baseline. Measures included tools to assess mood, burden, health, cortisol levels, behaviour and response to behaviour. No significant results were found for carers participating in the intervention. However they commented positively that the physical exercise had given them pleasure, improved mood, greater self-esteem and enhanced quality of relationship with their person with dementia; the support increased awareness of the importance of enjoyable activities and decreased loneliness.

A qualitative study of participants' views about the START intervention (STrAtegies for RelaTives) coping strategy for carers of people with dementia, Sommerlad, *et al.* (2014)

START (STrAtegies for RelaTives) is an eight-session manual-based coping intervention which aims to reduce depression and anxiety in family carers. This randomised controlled trial used self-completed questionnaires to analyse the experience of individual family carers of people with dementia who received the START programme. The study drew participants from 4 mental health services in SE England identified 173 carers recruited to the START programme and 87 in a control group (who received the usual support provided by their mental health services) all were living in their own homes. Carers in the START treatment group after 2 years were asked to complete questionnaires, 75 responded.

Responses were varied in respect of which components of the programme they found important, responses included: relaxation techniques, education about dementia, strategies to help manage the behaviour of the person with dementia, contact with the therapist and changing unhelpful thoughts. Two-thirds were continuing to use the START techniques at 2-year follow up. This indicates a possible mechanism for continuing efficacy after the end of the intervention: by having a copy of the manual and CD carers were able to revisit aspects of the therapy and adapt caring strategies as new needs arose. Few content changes were advocated, but more sessions and the involvement of wider family were suggested by some carers. Accessing the intervention shortly after diagnosis was felt to be appropriate.

Participants' varied responses suggest that a multicomponent intervention offering a range of strategies is appropriate to the differing needs of carers. The authors acknowledged possible response bias particularly in respect of obtaining views from carers who had withdrawn.

Randomized controlled trial of START psychological intervention in reducing abuse by dementia family carers, Cooper, *et al.* (2015)

This study looked to see if START (STrAtegies for RelaTives) reduced abusive behaviour in family carers of people with dementia. This was assessed using the Modified Conflict Tactic Scale (a self-completed measure of potentially abusive behaviour) at baseline, 4, 8, 12, and 24 months. The study identified 173 carers recruited to the START programme and 87 in a control group (who received the usual support provided by their mental health services). The study found no evidence of a difference in abusive behaviour between the groups or that behaviour changed over time. A quarter of all carers still reported significant abuse after two years, but those on the START programme not acting abusively at baseline did not become abusive and there was no increase in abusive behaviour as dementia symptoms developed.

Evaluation of the effectiveness of weekly cognitive stimulation therapy for people with dementia and the additional impact of enhancing it with a carer training programme, Cove, *et al.* (2014)

Cognitive stimulation therapy (CST) is an evidence-based intervention for people with dementia when delivered as a 14 session, twice weekly intervention. However many services in the UK deliver CST once a week for 14 weeks. This study aimed to evaluate the effectiveness of once weekly CST enhanced by a formal carer training programme.

The study was structured as a single blind, randomized controlled trial with 68 people with dementia and their carers recruited through community Memory Assessment Services. They were randomized to one of three cohorts: CST plus carer training, CST only, or control. Standardized measures of cognition, quality of life, and quality of relationship with carer were administered to the person with dementia at baseline and at the 15 week follow-up.

The CST intervention followed the format of the standardized CST manual. The 14 weekly 45 minute sessions began with the group song, followed by a warm up exercise and discussion of a recent news article. The main activity then followed, based on that week's theme. Sessions were designed to be as inclusive as possible tailored to the groups' abilities.

The carer training was adapted from the current CST training programme. Carers attended two sessions, with an optional workshop offered between the sessions. Session one lasted 3 hours and was delivered to coincide with the first CST group. Carers were given an overview of dementia and the CST programme including the 18 guiding principles of CST and ways of engaging the person at home according to these principles. Carers were given a workbook with activities relating to each CST theme which they could try with their person with dementia between CST sessions. The workbook contained a diary to record and rate the success of activities tried at home. Session two was 1 hour delivered during the final week of the CST programme. The focus was on maintaining the skills acquired. An optional 1 hour question and answer session was offered at week 7.

The aim of the programme was not to train carers to deliver CST, but to support skills in interacting with the person with dementia they care for, and to encourage them to implement CST activities at home. The objective was to empower carers so they could enhance the experience of the CST group for the person cared for. There were no differences in the people with dementia across the three groups at baseline or at follow-up; there were no significant differences in any outcomes. There were no improvements in cognition, quality of life or the quality of the caregiving relationship in those receiving weekly CST, with or without carer training. These results suggest that weekly CST may not have an impact, and the carer training programme cannot affect this. However the study did not measure all domains and there could have been benefits in socialisation and self-esteem for example.

The authors recommended that this study be replicated with a larger sample, and using a wider range of outcome measures to capture possible benefits missed in this study.

Full Report

Study protocol for the evaluation of Going to Stay at Home programme (a residential carer training program to reduce dementia carer distress and burden), Gresham, *et al.* (2014)

A 10-day hospital-based residential carer training programme developed in the 1980s was found to delay residential care placement, delay mortality and reduce carer's psychological morbidity. This study aims to evaluate the effects of a similar programme which has been adapted for use with residential respite. It will be a single-arm longitudinal study conducted at a residential care facility involving 100 people with dementia and their primary carers. Carers will attend a 7-day residential programme of intensive training sessions including didactic sessions, group work, modelling and role play while the people with dementia are engaged in daily activities. Data will be collected at baseline, at 6 and 12 months after completion of the programme. It is hoped this study will provide evidence on the effectiveness of the programme in reducing carer distress and burden as well as delaying institutionalisation of the person with dementia.

Timetable of the programme for carers

Day	Morning	Afternoon	Evening
Sunday		Welcome and orientation	Socialising
Monday	Combating isolation	Medical aspects of dementia Relaxation	Socialising
Tuesday	Fitness Reminiscence and reality orientation	Communication Assertion	Socialising
Wednesday	Re- roling Nutrition	Therapeutic use of activities Work simplification, organisation and safety at home	Socialising
Thursday	Nursing skills	Planning for the future Using community services	Carers' outing
Friday	Caring for self Relaxation	Carers' choice of topic	Socialising
Saturday	Farewell		Socialising

There is no evidence of multi-component, psycho-educational interventions for migrant and minority dementia caregivers in the UK. However, considering the evidence-base that reports factors that increase poor outcomes of caregiving for such communities, multi-component, psycho-educational interventions will benefit migrant and minority carers just as they would all dementia caregivers.

Psychological Interventions

Prevention of abuse, Drossel, *et al.* (2011)

A US study adapted a Dialectical Behaviour Therapy Skills (DBT) intervention for use with 16 caregivers of persons with dementia with high risk of elder abuse. The nine week intervention was given at a community clinic. Caregivers reported significant improvements in their psychosocial functioning, less fatigue, improved emotional well-being and were increasingly using problem-focused coping strategies. Depression scores had improved by at least 10% for 40% of the participants. The caregivers tended to make more use of individual therapeutic services during the period of group attendance, showing '*appropriate help- seeking behaviour in highly demanding situations*' (p.109).

Small 'booster groups' using the same DBT skills manual were implemented in response to requests from the participants, and six of the caregivers took part in these. Data from the booster groups suggested that high-risk caregivers may need on-going support to maintain their treatment gains. The authors suggest randomised controlled trials of this type of intervention, including an element of 'direct observations of the caregiver and the person with dementia under task demand conditions, to directly assess the use of skills versus resorting to coercive practices' (p.116).

An exploratory study of The experiences of therapy from the perspectives of carers of people with dementia, Elvish, *et al.* (2014)

Interviews were conducted with six carers of people with dementia about their experience of receiving counselling/Psychotherapy. The authors acknowledged that conclusions are tentative as this was an exploratory study with a limited sample. However the study identified three themes:

- 'Still doing the best I can';

- 'Feeling connected and being understood';

- and 'Wanting to share information with someone 'neutral'.

This study suggested that, by building an effective therapeutic relationship, therapy can provide a 'bridging' relationship and a 'safe space' for carers to disclose and share concerns which would help them through the changes dementia brings in their relationship with the person they care for. Carers in therapy appeared to demonstrate personal growth, decision making, capacity to take on new roles and improved self-confidence; even whilst they were experiencing a loss of conversation, reduced connectivity and a loss of shared activities.

Peer support and other social interventions

Gallagher-Thompson, *et al.* (2012) indicate that there are no randomised controlled trials to assess the value of support groups. However they and other authors indicate the value of social support in alleviating distress, bolstering support networks and engaging family networks (Elvish, *et al.*2012). They suggest that this is particularly where the needs of the family caregiver have been carefully evaluated, as not all caregivers want or benefit from such interventions; therefore it is important to establish whether social isolation is a choice or a consequence of their caregiving role.

Considering the perceived isolation for ethnic minority dementia caregivers, peer support and social interventions are important interventions for such communities. Health care providers should view low levels of social support as a possible precursor to poor psychological outcomes in ethnic minority caregivers (Clay, *et al.* 2008). Whilst not UK based, a number of studies inform our understanding of the types of

interventions that may be useful for migrant and minority communities living in the UK.

Churches play an essential role in the African American community and are instrument in serving a link between congregants and formal support services (Janice, 2008). Gerdner, *et al*. (2007) similarly found that the church played an integral part of the daily life of African Americans living in Arkansas Delta. The need for both emotional and practical support from community members for Sikh carers of a family member with dementia in Wolverhampton in the UK emphasises the important and influential role that temples could have for supporting people with dementia and their carers to live well (Jutlla, 2011).

Culturally appropriate activities for people with dementia and their carers is a good form of social support and psycho-social intervention for people with dementia and their carers. For example, Tilki, *et al*. (2010) note that Irish music is a major focus of the activities in Irish community organisations for all participants but plays a key role in expressing emotions by people with dementia. The numbers of people and organisations implementing creative therapies for people with dementia is growing fast – at local, national and international levels. Whilst these are usually small scale projects unique to their areas of interest, the short term benefits they have had for people with dementia have been well captured (e.g. Outhwaite & Killick 2012; Rylatt, 2012; Coaten, 2011; Newman-Bluestein & Hill, 2010; Cohen, 2009). Drawing on a larger critical ethnography that examined the lived experiences of families caring for people with dementia in India, Brijnath (2011) found that for this community, food offers ways to retain identity, build relations, improve function and show love: especially as certain foods are considered to have medicinal properties. Activities such as cooking, laying the table, feeding and eating build relations between family members and the cared-for person.

A recent study has focused on strengths perspectives or 'optimistic psychology', targeting interventions on reinforcing caregivers' capacities instead of only reducing their difficulties (Carbonneau, *et al*. 2011) This Canadian

study involved 49 caregivers, 26 in the experimental group and 23 in the control group. The intervention group was given a leisure education programme adapted for people with dementia. Caregivers received education sessions on their own and together with the person with dementia where they identified and practised activities they could do together. The programme helped caregivers to find suitable activities and to learn how to do them with the person with dementia. Although the quantitative results did not show a difference between the two groups, the qualitative data showed that the participants increased their self-efficacy in generating enjoyable moments with the person with dementia.

Outreach with family carers in social care organisations, Moriarty *et al*. (2015)

These authors carried out a study which aimed to describe different ways of working with family carers in adult social care departments. The study looked at four adult social care departments in England and undertook surveys and 86 semi-structured face-to-face interviews with funders, carers' workers, representatives of voluntary organisations and family carers.

85% of survey respondents reported that there was a carers' centre in their locality. Usually these were contracted with voluntary organisations, often the Carers' Trust. In some rural localities there was a more peripatetic approach to outreach, sometimes using drop-ins in church halls or a road show with a rolling programme of events which moved around the villages and towns and appeared to be a more accessible service.

They also found evidence of some models of outreach in primary care, particularly a carers' support worker attached to GP practices. There was very little evidence of peer support approaches embracing outreach. The study made the case for considering outreach as a strategy to tackle stigma and bring support to "hard to reach groups" for example BAME carers or LGBT carers. It also indicated the value of providing outreach to professionals to increase their awareness of carers' needs and support options. This study highlighted important differences between outreach and information

giving and concluded that organisations providing support for carers needed to consider the advantages and disadvantages of different models of outreach and which models would be effective in reaching specific groups of carers.

Investigation into Experience of Carers of People with Dementia and Volunteers of a Peer Support Scheme, Greenwood, *et al.* (2013)

This study investigated the experience of peer support volunteers and carers involved in a peer support service developed in South London. This was a small qualitative study providing a depth of data. The scheme comprises of one to-one support from trained peer supporters who had themselves been carers of people with dementia. The carers and peer supporters meet on a regular basis (usually one hour per week) for approximately 6 weeks, and peer supporters have telephone contact after each peer support session and monthly supervision from the service facilitator.

Analysis of interviews with 9 carers and 4 peer supporters identified 3 key themes: the perceived benefits of peer support, the supporter– carer relationship, and the challenges and limitations of peer support. Peer support helped both carers and peer supporters to appreciate that they were not alone in their feelings and experiences. The carers also appreciated opportunities to talk freely about difficult situations and gain coping strategies from the experience of the supporters. Carers identified the benefits of mutual problem solving with supporters. Carers felt the shared emotional journey increased supporters' empathy and also gave carers hope. Peer support also helped carers cope by giving them a different perspective on caring through appreciating the importance of their role. Both carers and supporters spoke of the value of helping carers recognize that the behaviour of the person with dementia was caused by the disease and was not the fault of the person with dementia or their carer. Supporters found their role rewarding, identifying satisfaction in using their own experiences to help others. They felt the supporter role helped them come to terms with their own

experiences and also appreciated the interaction with other volunteers.

These findings also highlight the isolation and exclusion experienced by current and former carers of people with dementia (the stigma and isolation of dementia may not end with the death of the person with dementia). Peer support was found to be beneficial for both peer supporters and carers. This impact on former carers is significant. Few drawbacks were identified by either party.

Some carers questioned the impact although they enjoyed the sessions. However these carers felt that no intervention that could have a significant impact, they often appeared to be those who were struggling more with their situations, they felt peer support could only offer short-term benefits.

A thematic analysis of the experience of family carers attending a joint reminiscence group with people with dementia, Melunsky, *et al.* (2015)

This was a qualitative study using semi structured interviews and thematic analysis to explore the experience of 18 family carers who attended 'Remembering Yesterday Caring Today' (RYCT) groups a part of a wider carer support programme: SHIELD (Support at Home: Interventions to Enhance Life in Dementia).

The RYCT intervention was developed by Schweitzer & Bruce (2008) as a structured psychosocial intervention for people with dementia and their family carers. In this study it ran for 10 months (12 weekly sessions followed by seven monthly sessions) facilitated by a trained team. Each two hour session followed a programme of topics encouraging reminiscence over the life-course (e.g. schooldays, going out, working-life).

Some of the carers were very positive; particularly enjoying engaging in social activity with their person with dementia and having contact with other carers. However others had more mixed feelings which included: regretting a lack of respite from their loved one (indeed finding the stress of getting the person to the session

outweighed any benefit); that the focus was on the person and had limited emphasis on their own needs; disappointment that positive impact on the person in respect of mood, memory, and confidence were short-lived; and some carers described additional stress and guilt through not being able (or having opportunity) to implement newly acquired skills.

In discussion of the findings the authors identified key learning in respect of the differing needs of spouse carers and children; they suggested that spouses may benefit most from respite, whereas children may gain most from interventions targeted at strengthening the relationship with the person they care for, thus groups targeted at subgroups of carers might be helpful. Also it was noted that carer expectations needed to be carefully managed, for example being explicit about limited time apart from the person with dementia.

A Systematic Review of the evidence of the Impact of Volunteer Mentoring Schemes on Carers of People with Dementia and Volunteer Mentors, Smith & Greenwood (2014)

This systematic review aimed at examining the differences and similarities between the various types of volunteer mentoring for carers (befriending, mentoring and peer support) and identifying the benefits for carers and volunteers. However only four studies met the inclusion criteria, 3 peer support studies and 1 on face to face befriending. This in itself indicates a paucity of evidence for the efficacy of volunteer mentoring and a need for further research. The befriending lasted for between 6 and 24 months. The befriending study found no significant benefits for either psychological well-being or cost-effectiveness. However, carers who received the befriending intervention for at least 6 months reported a statistically significant improvement in depression scores at 15 months, which suggests this merits further consideration.

The two studies on face to face peer support found no positive improvements in either depression or carer self-esteem, although secondary analysis found a modest effect on depressive symptoms for carers in the most stressful situations.

The third peer support study focused on telephone peer support for carers of people with dementia and stroke survivors and showed an increase in coping skills and caregiving competence and a decrease in loneliness and reliance on other forms of social support. The carers also valued emotional support their supporters provided. Peer supporters' first-hand experience of being a carer for someone with dementia was viewed as highly important by the carers. It was concluded that telephone peer support provides accessible, cost-effective, and beneficial support for carers.

Overall the findings of these studies illustrated how highly carers valued contact with people who had had similar experience. Significantly matching was not found to be essential for volunteer mentoring relationships to be effective.

National Evaluation of 40 demonstration sites for Dementia Advisors (DA) and Peer Support Networks(PSN), Clarke, et al. (2014)

The key aims of the research were to:

1 Describe the range of demonstration site services,

2 Assess the new service models in relation to their influence on the well-being of people with dementia and carers, contribution to the aims of the National Dementia Strategy for England and their place within the wider health and social care economy.

3 Identify ways in which DAs and PSNs contributed to the well-being and resilience of people with dementia and carers, with a focus on accessibility of services, involvement and information and support for making choices and independence.

Key data was collected from all 40 sites during eight separate weeks across an 18-month period:

• The average number of occasions that the services were accessed 14 to 19 per week per site.

- 56% of points of contact were with Dementia Adviser services. Of these, 63% were with carers.

- 44% of points of contact were with Peer Support Network services. Of these 44% were with carers.

- The majority (79%) of people accessing services were aged between 65 and 85, 9% of people accessing services were aged over 85.

- 12% of contact was by someone from a BAME community (this varied between sites).

The research used a mixed-methods design with three main strands:

1 activity and outcome monitoring;

2 organisational surveys and collaborative discussion;

3 in-depth case studies in eight of the 40 sites.

Key findings in relation to the needs of people with dementia and carers included:

- The timing and flexibility of support from Dementia Adviser and Peer Support Network services resulted in support that appeared to be well tailored to individual needs and circumstances;

- Peer support by and for people with dementia and carers was rooted in identification with others in a similar position, enabling greater confidence and more independence;

- Dementia Adviser and Peer Support Network services had a significant role in enabling people with dementia and carers to re-narrate their lives, finding a new life which, though different from life prior to dementia, had meaning and purpose and in signposting to appropriate other services and support;

- New social networks plus training and awareness raising activity enhanced social networks and

community awareness, both of which encouraged social inclusion; and

- The relationship of the demonstrator services to pre-existing services significantly influenced their work, tensions arose where boundaries and remits were unclear.

Specific conclusions and recommendations drawn from the evaluation have significant resonance for other service development. There is a strong recognition that peer support, advice and information are essential components of dementia care and services need to promote inclusion of people with dementia and carers within communities in a way that cuts across sector boundaries.

People have a need to re-narrate their lives in response to the diagnosis.

Organisationally the authors emphasise the importance of securing commitment to sustainability and finding the balance between service models: nationally vs locally driven; specialist vs generic provision; consistency of a singular 'model' vs flexibility to adapt to varying and changing individual and community need.

Exercise/ Physical Activity Based Interventions

McLaren, *et al.* (2012) in their systematic review of interventions to delay functional decline identified a link between functional decline in people with dementia and the level of burden experienced by family caregivers. Their review has indicated that early results from trials have demonstrated that it is possible to delay functional decline and thus influence caregiver wellbeing. However the authors indicate that these results should be treated with caution, as further longer term research is needed to establish whether these results can be sustained and furthermore, whether they can achieve clinical significance. Examples of recent activity based programs include the following study by Canonici, *et al.* (2012).

Canonici, *et al.* (2012) A motor intervention program

These authors sought to deliver an intervention which would improve mobility and therefore decrease caregiver

experience of burden. 32 people living with dementia and their family caregivers participated, with half being assigned to the control group. 60 minutes of exercises were delivered, 3 times per week over 6 months to improve agility, flexibility, strength and balance. The people with dementia in the intervention group showed reduced functional decline when compared with those in the control group. Family caregivers also demonstrated reduced levels of burden.

Media based interventions

More recently, some studies have integrated technological advances into their design, which have the potential to overcome some of the challenges associated with translating research findings into practice, including the cost of repeated face to face interventions, or of delivering services within rural locations. These studies include: Marziali and Garcia (2011) Internet Chat Support including access to a handbook and videos

These authors carried out a quasi-experimental study of the impact on caregivers' levels of stress and mental health status for people with dementia of using technology to access intervention programmes. Participants were 91 caregivers, 72% female, and 74% spouses, who were offered a choice of an internet chat support group which included access to a handbook of caregiver information and six videos on managing caregiving, or an internet video conferencing support group facilitated by a clinician, along with the caregiver information handbook. The video conferencing support group had significantly greater improvement on mental health status and improvements in self-efficacy, neuroticism, and social support. Qualitative analysis showed that participants in the video group '*experienced relief in being able to express openly negative feelings that were perceived as unacceptable in a family caregiving situation*' (p.41).

Video based coping skills training and telephone coaching, Williams, *et al.* 2010

A controlled clinical trial in the US examined the value of video-based coping skills training along with telephone coaching to reduce psychosocial and biological markers of distress caregivers of people with dementia. The participants were 116 caregivers who were assigned to the intervention group or a waiting list. Participants viewed two modules a week of a life skills video adapted for dementia caregivers, and received telephone coaching and homework. They were assessed before, after and at three and six months follow-up. The intervention was found to significantly improve depression, anxiety, perceived stress, and blood pressure which were sustained over the six-month follow-up period.

Evaluation of DEM-DISC, a customized e-advice on health and social support services, Van Mierlo *et al.* (2015)

This study aimed to evaluate and improve DEMDISC. DEM-DISC is a Dementia-specific Digital Interactive Social Chart (developed and used in the Netherlands) as an ICT tool to support carers of people with dementia and professionals.

It provides information on health and care services for people with dementia and carers incorporating the facility for carers to manage their own support by guiding them through a process of clarifying their needs and providing them with customized answers about potentially relevant care services in their area. It also supports professionals in disease management.

DEMDISC starts with several standard questions, carers select the most appropriate need. A tree structure of questions then leads carers to specific proposals to meet need. It gives advice on details of the care and support services suggested and access arrangements. DEM-DISC provides an interface with individualised answers provided by the carer and links to relevant (regional and national) organisations.

A cluster (RCT) design was used with measurements at baseline, 6 and 12 months. In the intervention group, 41 carers and 13 case managers could access DEM-DISC during twelve months. The control group, 32 carers and 14 case managers, had no access to

DEM-DISC. The primary outcome measure of this study was the Dutch version of the Camberwell Assessment of Needs for the Elderly (CANE), however a number of additional tools measured symptoms, competence and quality of life. Carers who used DEM-DISC for twelve months reported an increased sense of competence than those in the control group. A subgroup of users who frequently accessed DEM-DISC reported more met needs after six months than those who had no access to DEM-DISC however they also reported more needs in general, including more unmet needs (possibly attributable to the broad range of topics covered by DEMDISC, which may have prompted them to consider topics of which they had been previously unaware. Overall informal carers and case managers found DEM-DISC easy to learn and user-friendly (though some used the system more than others). The need to find ways to keep the information on DEM-DISC updated is acknowledged to be important.

A study of a telehealth behavioural coaching intervention for female family carers, Steffen & Gant (2016)

This US study examined the impact of two telehealth programmes on women caring for a person with dementia. The first of the two programmes comprised of a 14-week intervention using video materials, workbook and telephone coaching in behavioural management, planning enjoyable and relaxing activities. The second programme comprised of a basic education guide and telephone support. Masters level students across a range of relevant disciplines were used to provide the behavioural coaching, which was successful as long as they received the appropriate training and supervision. The study conducted telephone interviews at baseline, post-intervention, and 6 months following intervention. It should be noted that the carers were supporting people with a range of mental health issues including but not exclusively dementia, also the sample size was relatively small (74 in total: 33 carers in the behavioural coaching intervention and 41 in the basic education programme), therefore outcomes in respect of carers of people with dementia are tentative.

At post-treatment interviews those who were part of the first programme (which included behavioural management coaching) had fewer depressive symptoms, negative mood and distress resulting from experiencing challenging behaviour than those in the basic education and support cohort. Carers reported valuing the time they spent discussing their concerns with intervention staff. Caregiving self-efficacy scores for accessing respite and managing behaviour that challenged were also higher in the cohort who received coaching. However these were found not to be maintained at the 6-month follow-up. In summary this study indicated that the telehealth behavioural coaching programme had greater efficacy than the basic education and telephone support. However the authors suggested that as modest benefits were not maintained at the 6-month follow-up carers of people with dementia in particular may need more than 14 weeks of contact. The potential benefits for people living in rural areas and the cost effectiveness is highlighted.

Acceptability of a guided self-help Internet intervention for family caregivers, Pot, et al. (2015)

This study explored the appropriateness of a guided self-help Internet intervention "mastery over dementia" (MoD) in terms of reach, adherence and user evaluation.

The intervention aims at reducing the psychological distress of carers of people with dementia.

The programme was designed with 8 sessions based on evidence from studies on other internet interventions.The sessions (largely based on CBT techniques with psycho-education, problem-solving, and time management) are delivered in order following themes:

1 Coping with behavioural problems

2 Arranging help from others

3 Time for yourself

4 Thinking and feeling

5 Not-helping thoughts

6 Helping thoughts

7 Stand up for yourself: assertiveness

8 Communicate problems

Booster session

The programme includes a public domain with information for carers on dementia, including a demo, self-test, and two short films of people who finished the intervention. This is followed by eight lessons, each with the same structure: (1) introduction; (2) questions about the previous lesson (not in the first lesson); (3) theory; (4) assignments, (including completion of a care diary), and; (5) an evaluation of the current lesson including a summary. Each participant has a coach (a psychologist) who communicates using a secure environment. After each lesson the participant sends homework and diary to their coach who responds with feedback to consider before the next session.

It is notable that whilst 149 participants commenced the programme, only 66 completed, the percentage of carers who did not complete was high (55.7%).

Key findings included: older carers participated in the intervention, the oldest being 87 years old; two-thirds of the carers participated in the intervention soon after diagnosis or within two years,; some carers had a loved one in a care home but still found it helpful; females rated higher on the comprehensibility of the lessons and feedback and spent less time on the lessons.

This study showed that a guided self-help Internet intervention like MoD is acceptable for a broad range of family carers of people with dementia in terms of reach and user response, although the relatively high attrition rate needs consideration. Cost effectiveness has yet to be established.

A systematic review of Effectiveness of computer-mediated interventions for informal carers of people with dementia, McKechnie, *et al.* (2014)

This review evaluated 14 studies into the outcomes of computer mediated interventions. Nine studies were of interventions delivered mainly or solely using the Internet. One study used a computer-mediated automated interactive voice response intervention; two, used a computer–telephone integration system; one used a DVD programme; and one used computer based education (not internet) . Education was the core of all programmes: three delivered education and professional support; two combined education with general support. One study compared education and professional support with education and more general peer support.

Generally, higher quality studies found that interventions had an effect on carer burden/stress and depression. Two higher quality studies also found that anxiety was reduced following intervention. Most studies found that the interventions increased positive aspects of caring and self-efficacy. Results were mixed in respect of social support, and physical aspects of caring did not appear to be affected. The interventions appeared to be well accepted by the carers. However only one intervention was continued after the evaluation, which may need further consideration as the accessibility and longevity of computer based interventions should be a key asset.

In summary the findings supported the provision of computer-mediated interventions for carers of people with dementia. The review suggested that programmes would benefit from clearly defined aims, and their evaluations needed a control group, adequate statistical power, and to measure more factors identified as important by carers.

A Pre-Post Cohort Study on The Effectiveness of an Internet Support Forum for Carers of People with Dementia, McKechnie *et al.* (2014)

This study explored the impact of Talking Point, the Alzheimer's Society's online forum for carers of people with dementia. The study focused on new users

of the forum in the period July 2012 to January 2013 during which 4177 new users registered on Talking Point. Participants accessed a survey through a link on the forum's home page, this survey involved baseline and 12-week follow-up measurements of new forum users' depression, anxiety, and quality of relationship with the person they cared for. 128 new users completed the baseline survey but only 61 completed both baseline and follow up measures. There were also 8 semi structured interviews conducted face-to-face or by telephone.

From the data available from 58 participants, usage of the forum was low. 17 (29%) reported that they had not visited the forum at all over the 12-week study period. 44 (76%) participants visited the forum fewer than 12 times over the 12-week study period. Of those who visited the forum, 18 (44%) never replied to any posts, and 20 (49%) never started their own new thread or post.

There was no change in users' depression or anxiety over the 12-week study period. However there was an identified improvement in the quality of the relationship with the person with dementia. Interview participants reported a range of positive experiences and benefits from using the forum. Qualitative data provided examples of carers learning strategies to interact with their person with dementia which they felt made them a better carer, also the opportunity to connect with people who had like experience reduced isolation and loneliness, and enabled them to "let off steam" to others in a similar position.

Limited negative experiences were also reported. Some interviewees expressed concern that some contributions seemed judgmental or inappropriate. They felt moderators (such as found on Talking Point) were important to ameliorate this. Others found hearing experiences of people who were struggling with worsening symptoms was distressing and made them fearful of the future.

One of the limitations to this study was the low usage rate of the forum which reduced the reliability of any assessment its impact and skewed the data.

Telephone based intervention following placement in long term care, Davis, *et al.* (2011)

These authors carried out a randomised controlled trial in the US of telephone-based intervention to support family caregivers through the process of adjustment after placing a relative with dementia in long-term nursing care. The intervention group received ten telephone contacts over three months. The calls were made by a qualified therapist using a manual with guidance on generating solutions and interventions with the family caregiver and matched to their situations. The results showed a significant reduction in feelings of guilt related to placement and more positive perceptions of interactions with staff, compared to controls, and most were satisfied with the service. The authors say that the sample size was too small to show evidence on the possible mechanisms of change but that the results show that telephone intervention is a potentially efficacious brief targeted psychosocial intervention for family caregivers going through this adjustment.

A systematic review of Internet-based supportive interventions for caregivers of patients with dementia, Boots, *et al.* (2014)

The intervention types, pattern, frequency and duration of interventions differed widely, as did the methodological quality of the included studies. The overall level of evidence was low but the results demonstrated that Internet interventions for informal dementia caregivers could improve various aspects of carer wellbeing, improving confidence, depression, and self-efficacy. However to achieve this interventions needed to have multiple components and be tailored to the individual carers. Furthermore, it found that carers could benefit from interaction with a coach and other carers.

Assistive Technologies

Gallagher-Thompson, *et al.* (2012) suggest that assistive technologies are another possible aid to support independent living, and improve quality of life for the person and their family caregivers. They further suggest that devices such as alarm sensors and pill dispensers

could potentially reduce burden. However limited literature exists concerning the use of such technologies and their impact upon the well-being of family caregivers. Furthermore, ethical considerations are evident, including the need to balance autonomy with independence (Landau, *et al*. 2010). These authors reviewed the use of electronic tracking devices and overwhelmingly indicated that such devices were useful, particularly because they allowed them to identify where their relative with dementia was in 'real time' and therefore provided them with peace of mind. A further study, exploring the usefulness of assistive technology for people with dementia (ENABLE), also found that family caregivers valued tracking devices, even though these were used infrequently by the person with dementia (Cahill, *et al*. 2007). Other devices in this study that were felt to be useful, reduce stress and promote independence included a night and day calendar, a picture button telephone, and a lost item locator. Kenigsberg, *et al*. (2016) indicate a possible role for the developing field of sophisticated e-learning and educational gaming both in developing skills and quality of life.

However, further research is required to establish the impact of assistive technology for families affected by dementia.

(2015) In-Home Occupational Performance Evaluation for Providing Assistance (I–HOPE Assist): An Assessment for Informal Caregivers, Keglovits, *et al.*

The In–Home Occupational Performance Evaluation for Providing Assistance aimed to guide interventions such as architectural changes, assistive devices and activity modification and measure their impact on informal caregiving in the home. It was developed by modifying an existing tool so that it identified environmental barriers to caregiving activities. It was tested on 31 informal caregivers and demonstrated reliability, good internal consistency and validity with existing measures. To date there is some limited evidence to suggest that home modifications improve caregiver outcomes but research is limited by a lack of validated instruments for measuring caregiver self-efficacy and assistance with practical caring activity in the home, the authors aspired to this tool supporting this gap.

"Carpe Diem" Supporting Conversations between Individuals with Dementia and Their Family Members, Karlsson, *et al*. (2014)

This study explored the use of a digital photograph diary (DPD) as a memory tool and to stimulate conversations about daily life between the person with dementia and their family carer. Seven couples tested the DPD for 6 months. Data was collected in three sequences using interviews, observations, and screening instruments. Some couples became regular users, while others used the DPD more sporadically. Factors contributing to regular use were: how the DPD matched expectations, actual use, support, experienced usefulness, and reactions from family and friends. Regular users found that the DPD stimulated conversation about recent activity. The authors found limited evidence in using multimedia technology in life story work and reminiscence and therefore suggested that technology which facilitated sharing life story memories might enhance the quality of life and relationship. The equipment comprised of 3 elements: a wearable camera which one of the couple wore during activities and which automatically took photos every 2 minutes, an adapted smart phone with GPS to identify picture location and a touch screen computer with software to sort photos. When viewing photographs the carer was encouraged to get the person with dementia to narrate the events. The key findings were:

- During introduction of new digital devices among people with dementia, communication of the aim and functions as well as how these match the user's expectations is important.

- Acceptance and integration of a device such as the digital photo¬graph diary (DPD) is a process that requires time, active support, and experience of use over time.

- The DPD contributed to increased communication and promoted the relationship between family members.

- The use of the DPD was perceived as a stimulating joint activity by the individuals with dementia and family members.

Gaps in the research concerning psychosocial interventions

A number of gaps are evident when exploring the research concerning psychosocial interventions. These are summarised here:

- There is a need for further investigation of interventions which are excluded from most studies because they do not meet evidence based standards, for instance, e.g. grass-roots derived caregiver support groups (Gallagher-Thompson & Coon, 2007) and complementary and alternative therapies which may be a valuable addition for a range of caregivers and particularly welcomed by some migrant or minority groups (Korn, *et al.* 2009).

- Despite prevalence studies pointing to high levels of elder abuse (Cooper, *et al.* 2008) and strong evidence that a number of caregivers admit to abuse (Pérez-Rojo, *et al.* 2009; Cooper, *et al.* 2010; Wiglesworth, *et al.* 2010; Yan & Kwok 2010), few studies have looked at interventions with caregivers to reduce the risk of abuse (Owens & Cooper, 2010; Drossel, *et al.* 2011; Cooper, *et al.* 2015).

- More research (including participation of caregivers and community groups) is needed on how to provide accessible and appropriate, targeted information about dementia and available services to ensure that people with dementia and their and family carers can be aware of early signs of dementia and seek help at an early stage (Robinson, *et al.* 2009; Leung, *et al.* 2011).

- Further evidence is needed on accessible, practical interventions for caregivers' physical health, including work on encouraging caregivers' self-care, exercise and healthy living, and promoting sleep, especially for women and caregivers from cultural groups that place a high expectation on family members to care

for others and those identified as suffering chronic stress (McCurry, *et al.* 2009; Connell and Janevic 2009; Vitaliano, *et al.* 2011; Glueckauf, *et al.* 2012; Gouin, *et al.* 2012).

- Implementation studies are needed on how to make existing interventions which are known to have an effect on burden, stress and depression available more widely to people from a range of cultural and ethnic groups, people in rural areas and others that might otherwise be excluded from services. Methods could include use of telephone and technology which have been shown to be helpful where caregivers can access and use it, and enlisting community groups and networks to help provide interventions (Stevens, *et al.* 2009; Marziali, *et al.* 2010; Thinnes & Padilla, 2011; van Mierlo, *et al.* 2012; Steffen & Gant, 2016)

- More research is needed on what helps families who are caring for a younger person with dementia (Bakker, *et al.* 2010).

- Evidence is required to understand what works for families who are affected by less common forms of dementia (La Fontaine & Oyebode, 2013)

- More long term follow-up studies would help to better assess the sustainability of outcomes of interventions, and the differing needs caregivers have at different stages (Kim, Chang, *et al.* 2011).

- Research should, where possible, give more attention to sub-groups of caregivers and the difference in outcomes from intervention for these groups. (Kim, Chang, *et al.* 2011; Van Mierlo, Meiland, *et al.* 2011).

- No research has been identified which compared income groups, or social class groupings, and no research has addressed interventions for LGBT caregivers or persons with dementia,

- More research is needed on interventions for the specific cultural and ethnic groups living in the UK.

What might a service be like?

This section considers a number of issues that are relevant to the design and delivery of a service. Firstly, it is recognised that a range of factors influence the success of interventions that will be relevant when considering what might be provided including the staff skills and knowledge. Secondly, although there is an increasing evidence base for interventions that are provided through new media such as the internet or videoconferencing, many existing interventions are at least in part group or family oriented and face to face, and thus frequently require a physical space for delivery. Consequently this section will also consider the environmental design issues that might need to be considered.

What factors will influence the success of a service?

In addition to the issues raised in previous sections, including length of intervention, and the appropriateness of the intervention to the needs of individual caregivers, various reviews point to other factors that will influence the success of programmes. These are:

1 That interventions should clearly identify the theoretical framework/s influencing their design and delivery (Elvish, *et al.* 2012; Gallagher-Thompson, *et al.* 2012).

2 That a comprehensive and individualised assessment of the needs of the family caregiver should be carried out and used to inform the type of intervention delivered (Gallagher-Thompson, *et al.* 2012; Zarit, *et al.* 2010; Family Caregiver Alliance, 2006).

3 A considerable body of evidence points to the need for the staff who deliver interventions to have appropriate training and be knowledgeable and skilled in delivering assessments and interventions. This includes knowledge about dementia, appropriate levels of empathic skills

and knowledge of local services and resources (Gallagher-Thompson, *et al.* 2012; Elvish, *et al.* 2012; deVries, *et al.* 2010).

4 That evaluation of the efficacy of the interventions should be built into the interventions at regular intervals so that appropriate adjustments can be made. Such evaluations need to be linked to the theoretical framework informing the intervention (Gallagher-Thompson, *et al.* 2012; Elvish, *et al.* 2012).

The Built Environment

While some forms of intervention may be most appropriately delivered in a person's own home, it is evident that facilities will be needed to provide a combination of individual group and technology based interventions.

There is also evidence to suggest that design and location are key factors in promoting social wellbeing for older people (Evans & Vallelly, 2007). Several papers have focused on the benefits of assistive technology (AT) for older people. For example, Lansley, *et al.* (2004) reviewed the use of AT and adaptations in various settings and concluded that they can both supplement and substitute for care services and that for many older people adaptations and AT can be cost effective, with relatively short investment pay-back periods.

A number of authors have attempted to draw on research evidence and common practice in order to develop design guidance for developers. For example, Vallelly and Evans (2006) proposed a range of environmental features that can support people with dementia: creating small, familiar environments; incorporating unobtrusive safety features; good signage; and the use of colour, lighting and architectural landmarks to aid orientation and way-finding

Design is also at the heart of the Maggie's Cancer Caring Centres model, where the architectural

principles include buildings that feel safe and welcoming, while helping people to cope with challenging situations and promoting a sense of connectedness (Heathcote, 2006).

Where will a service be provided and what influence will location have on the provision of services?

The location of a service will have a reciprocal influence on who accesses the service and what is delivered. Individuals and communities are likely to have a range of diverse beliefs influencing their willingness to access services. For example, it has been acknowledged that service provision can be deemed inaccessible or stigmatised because of what it represents; this is particularly the case for services for people who are deemed to have mental health difficulties (Hibbert, *et al.* 2008).

Furthermore, the diversity in the population of a particular location will be an important consideration. For example, just as experiences of caring for a person with dementia differ by culture and country

of residence (Wu *et al.* 2009), they will also differ by location (Jutlla 2011). The communities residing in the chosen area need to be understood within their migration and historical context so as to understand the social, community and political forces that have impacted on their lives (Gerdner *et al.* 2007; Mackenzie 2007; Tilki *et al.* 2010; Jutlla 2013).

Finally, rurality will also be an important consideration. Rural areas experience particular challenges in providing dementia services including travel costs, limited resources; time to travel; stigma and difficulty in recruitment of staff involved in delivering services. A recent systematic review has considered the scientific literature on service provision in rural and remote settings (Morgan, *et al.* 2011). This review has highlighted some specific recommendations for the provision of remote and rural services including the use of telecommunication technologies to deliver dementia specific training to staff and to overcome professional isolation. They also identify that tele-health videoconferencing can be effectively used to provide some aspects of service provision.

'While some forms of intervention may be most appropriately delivered in a person's own home, it is evident that facilities will be needed to provide a combination of individual group and technology based interventions.'

Who will the service be for and how can family caregivers be supported to access a service?

This review has highlighted that a range of family caregivers are involved in caregiving including:

- Spouse/ partners of people living with dementia (including long-term marriage and partnerships, those in second relationships and partners in LGBT relationships).

- Adult children, including daughters, sons and their partners/ spouses.

- Children and young people with a grandparent or parent with dementia.

- Siblings and friends may also be involved in caregiving. A wide range of family caregivers, influenced by diverse backgrounds, ethnicity, sexual orientation, relationship and gender are therefore likely to be involved in caregiving and may benefit from tailored interventions.

However, it is worthwhile considering the evidence from recent studies which have highlighted the benefits associated with psycho-social interventions which seek to improve the quality of life for both the person with dementia and their family members (Cooper, *et al*. 2012; McLaren, *et al*. 2013; Elvish, *et al*. 2012; Gallagher-Thompson, *et al*. 2012; Droes, *et al*. 2006; Smits, *et al*. 2007). These studies indicate that combined interventions, including goal setting, environmental assessment; development of carer coping strategies, opportunities for relational work and psychological support demonstrate improvements in quality of life for both the person with dementia and their family members, and are viewed to be successful interventions. This is not to suggest that all interventions within this model are delivered together, but rather as demonstrated in the Meeting Centres Support Programme, they can be provided through joint and individual sessions

(Cooper, *et al*. 2012; Elvish, *et al*. 2012). Furthermore, some suggest that it may be necessary to include the wider family in some aspects of these interventions, because they are directly affected by the experience of dementia; they may also be providing care and because they may provide additional support to the family member primarily involved in caregiving and the person with dementia (Mittleman, *et al*. 2008; Nunneman, *et al*. 2012; Rolland, *et al*. 1994; La Fontaine & Oyebode, *et al*. 2013).

How can people be supported to access the service?

Interventions that respond flexibly to the needs of different families, including work and other commitments have already been highlighted such as internet, video or telephone conferencing strategies for delivery. Key to delivering these however will be the availability of such facilities for family caregivers. It is possible that older people who are caring for spouses or partners with dementia may not have access to such facilities and this will need to be considered in the provision of such services. However, it is likely that many younger family caregivers will have access to these facilities, now and in the future, and evidence suggests that they are well received by these groups (Gallagher-Thompson, *et al*. 2012). Furthermore, there is evidence that family caregivers find access to interventions difficult when they are unable to leave the person they are caring for alone. Consequently, if interventions do not include the person with dementia, then consideration will need to be given to how support to attend can be facilitated (Barnes, *et al*. 2013).

Accessibility issues are of particular concern when considering migrant and minority communities. It is evident from the research that migrant and minority family caregivers would benefit from a service that is well linked into the local communities for which it is serving.

Migrant and minority communities are not homogenous and have different cultural needs both

across communities and within them. The service should demonstrate a value base that promotes inclusivity by treating such members as individuals alongside the knowledge of the social and political influences in their lives as migrants (Mackenzie, 2007). Currently, voluntary organisations have been responsible for providing support for their community (e.g. Tilki, *et al*. 2010). It has also been suggested that community-based outreach approaches should embrace an appreciation for caregivers' faith development, expressions and experiences of spirituality.

Clinical interventions need to more proactive in responding to spiritual/religious issues (Farran, *et al*. 2003). More research is needed on coping and spirituality – this could serve as a basis for helping other caregivers employ better coping strategies. Interventions should be based on the needs of the individuals, families and communities in receipt of the service. Further research on service and care needs

along with developing culturally sensitive instruments for assessing cognition, psychiatric symptoms, personality changes and daily activities is needed (Karim, *et al*. 2011).

A service should be inclusive of all migrant and minority dementia caregivers including those British born as they may be in need of support due to issues of cultural and intergenerational conflict. Based on the evidence, additional work may be required to access migrant and minority communities and encourage them to engage with the service – particularly the older generation who may also have language barriers. Research on dementia care in ethnic minorities in the UK concluded four major challenges/needs in this area; understanding life histories and migration experiences, understanding culture and community norms when caring for a family member with ementia, raising awareness and tackling stigma, and making services culturally competent (Jutlla 2013; Jutlla, 2015).

'There is evidence that family caregivers find access to interventions difficult when they are unable to leave the person they are caring for alone. Consequently, if interventions do not include the person with dementia, then consideration will need to be given to how support to attend can be facilitated.'

'Interventions should be based on the needs of the individuals, families and communities in receipt of the service.'

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